

“Because It Breaks Your Heart”: A Study of Transformational Learning
Among Adults With Cancer

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Abstract

Despite provincial improvement efforts, quantitative patient satisfaction survey results for adults with cancer consistently indicate lower satisfaction with how healthcare professionals address their emotional and information, education, and communication needs. These emotional and cognitive needs greatly influence how adults perceive their care experience. More information is needed about adult cancer patients' cognitive and emotional needs to understand how to improve their experience and satisfaction with their cancer treatment and care. Qualitative methods such as narrative inquiry have the potential to provide greater insight into adults' personal experience. This qualitative, arts-informed narrative inquiry examined how illness narratives and arts-based artifacts can deepen understanding of the cognitive and emotional needs of a cohort of adult women with cancer. Purposeful sampling was used to select 6 adult women with cancer who had experienced diagnosis, treatment and were living with cancer. Data collection methods included semi-structured interviews and the researcher's journal notes. Data analysis revealed additional connections between themes derived from the women's illness narratives and their arts-based artifacts. These findings were further illustrated by creating a collective body-map. Results demonstrate how arts-based methods expand what is known about the cognitive and emotional needs of adult women with cancer and provide adult educators with direction for planning transformative education. The study discusses implications for transformational adult education practice and educational research, and offers some initial thoughts on the use of arts-based methods to foster perspective transformation. The study will be of particular interest to adult educators who are interested in promoting transformational learning for doctors, other healthcare professionals, and adults with cancer.

Keywords: adults, cancer, narratives, artifacts, body-map, transformational

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It has been a long and interesting journey as a part-time doctoral student. Certainly, no one makes this journey alone.

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Elder Julie Ozawagosh first taught me the value of stories, and with her teachings offered trust and friendship. Miigwetch, Julie.

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Countless family members, friends, and neighbours have remained lined up along the route to the finish line, encouraging and cheering me on. Thank you for believing.

Dedication

This work is dedicated to Taryn, Eva, Erin, Loraine, Holly, and Erica¹, the women who trusted me with their beautiful and compelling stories and shared their personal artifacts, personal spaces, fears, hopes, and dreams with me.

It has been an honour to do this work for and with you.

I also dedicate this work to my family and friends who have walked and are still walking with cancer, and to their devoted caregivers: Helen and Dmytro, Borys, Maxine and Ron, Ron Jr., Diane, Mary Lou and Mike, Anne, and Suzanne and Claude. Time will not diminish the memory of the joy and laughter that you brought to my world.

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I say to those who will embark on a similar life-altering journey one day: I hope that the stories that Taryn, Eva, Erin, Loraine, Holly, and Erica shared will make a difference to your experience of care. I have hope.

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¹ Pseudonyms.

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Prologue

AVAtar: What will you do with our stories?

Researcher: I will write about your stories, and share what I write with doctors and
educators at conferences and in journals.

AVAtar: Will they see and hear me?

Researcher: I will also draw pictures and write poems to touch their hearts and open
their eyes and ears.

AVAtar: Will our stories make a difference?

Researcher: If I tell your stories well, they will.

AVAtar, (see p. 142, para. 2).

CHAPTER ONE: INTRODUCTION TO THE STUDY

I have had the opportunity to reflect on my life's work as a radiation therapist, an adult cancer educator, and most recently as an administrator while I conducted this research and created this dissertation. In this sense, I am looking through my rear-view mirror while I write these words. The rear-view mirror metaphor describes my belief that "the past can be critically held: 'it now makes sense'" (Garbutt, 2017, p. 277). I can trace the path I have taken, and review and question the choices I have made. My path, from naive clinician to sensitive educator, and curious researcher now makes more sense to me.

I have worked in the field of radiation oncology, the treatment of cancer with radiation, for more than 35 years. As a healthcare professional, adult educator, and social being, I am situated in cancer stories. I am invested in the education of cancer patients, healthcare professionals, and students. As I reflect on how I have been impacted personally through the cancer stories of family and friends, and professionally by the stories of cancer patients, healthcare professionals, and students, I question if I have positively influenced their experience. When I provided care as a radiation therapist, did I do enough to help my patients manage both the physical and emotional side effects of radiation treatments? When I worked with radiation therapy students in the clinic and the classroom, did I help them see and feel that a cancer patient is a whole person, not only a physical body with a disease? As an adult educator and administrator, did I treat everyone in my classroom with respect and dignity, as I would wish to be treated? These questions seem more urgent now.

I may never know the true impact of my life's work on others, but by recalling people and events from the past, like images in the rear-view mirror, their stories can "haunt us according to our current susceptibility and receptivity to the messages the accounts hold"

(Garbutt, 2017, p. 280). I remember the stories of people I have served most clearly. Even though I am receptive to the meanings of my personal and professional experiences, I still struggle to understand how the power, privilege, and the positions that I held affected my interactions with adult cancer patients, other healthcare professionals such as doctors and nurses, and medical and radiation therapy students. As I look forward, I ask myself, “What personal biases do I bring to the table? What do I not see and hear that is critical to my understanding of illness and my ability to help others? What more can the experiences of adults with cancer teach me that I can share with healthcare professionals and students, cancer patients and family members and other individuals in the community?” How can looking at their experience help me to “reimagine our world and put that reimagining into effect for an improved future” (Garbutt, 2017, p. 280) in adult education? These personal questions shaped the research that I will describe in this dissertation.

Background and Rationale

A visit to the doctor is a common experience to which most of us can relate. We may recall our experience as positive or negative, or in many cases, we may not assign a value to the experience unless there was a significant event associated with the visit. Learning that we have a serious illness, especially one that is life-threatening like most cancers, may make us more aware of the encounter and cause us to focus our attention on the personal interaction that takes place between us as the patient, and the doctor as the expert. The interactions we have with doctors and other members of the healthcare team when we have cancer can influence how we perceive and understand the experience and the decisions that we make about our care, regardless of our personal circumstances, or where we live in the world.

Although children, adolescents, and young adults do develop cancers, overall, cancer is

primarily a disease of aging. The median age of cancer diagnosis is between 65 and 69 years of age; since Canada's population is aging, the number of people diagnosed and living with cancer will continue to increase over time (Canadian Cancer Society, 2017, p. 29). Canadian cancer statistics are sobering: the probability of developing cancer, based on current incidence rates, is 45% for women (a 1 in 2.2 chance), and 49% for men (a 1 in 2 chance) during their lifetimes. The current mortality rates indicate that 24% of women (a 1 in 4.2 chance) and 28% of men (a 1 in 3.5 chance), or approximately 1 out of every 4 Canadians, will die from cancer (Canadian Cancer Society, 2017, p. 46). Cancer has a very real potential to affect us and the people we love. Because of cancer prevention education, the earlier diagnosis of cancer and new cancer treatments available, people who are diagnosed with cancer are more likely to survive 5 or more years after their diagnosis. The increased likelihood of having and living longer with cancer highlights the importance of the information and education about cancer, treatment and living with cancer, as well as the emotional support that oncology healthcare professionals might provide. Since doctors and other healthcare professionals are expected to provide information, education, and emotional support during their clinical encounters with adult cancer patients, good dialogic communication should be important.

The Cancer Quality Council of Ontario (CQCO) provides advice to Cancer Care Ontario and the Ministry of Health and Long-Term Care regarding improving the quality of cancer care in the province. The CQCO monitors and publicly reports on the performance of the cancer system using quantitative survey methods and data. Among other areas for improvement, these data demonstrate the need to improve the communication and teaching skills of healthcare professionals, which are components of the relationship between doctors and healthcare professionals and people with cancer. For example, in 2016, the average cancer patient

satisfaction score for concerns related to receiving enough information, education and communication from their oncology healthcare professionals in Ontario was 66.5% (Cancer Quality Council of Ontario, 2016). Cancer Care Ontario (CCO), an agency of the provincial Government of Ontario responsible for improving cancer services, funds cancer centres to provide cancer care and expects each centre to engage in activities to improve the adult cancer patient's overall experience of care. Despite this directive, the scores for information, education, and communication have not changed significantly (e.g. 2013/14: 66.6%; 2014/15: 68%; 2015/16: 66.5%; CQCO, 2016). The scores for emotional support are cause for even greater concern. For the same reporting period, 2013-2016, adult cancer patient satisfaction with the emotional support they received from their oncology team remains at 55% (CQCO, 2016). Through satisfaction survey scores and anecdotally, adult cancer patients are telling administrators, doctors, and other oncology healthcare professionals that they should (a) provide more information about what adults with cancer can expect when diagnosed with and treated for cancer, (b) improve the ability of healthcare professionals to communicate and teach adults, and (c) ensure that adults with cancer receive the emotional support that they need.

Based on my experience working within the cancer system, I can attest that administrators pay more attention to patient satisfaction survey scores than do busy doctors. Mehta (2015) attributes doctors' lack of attention to patient satisfaction survey scores to the perception of many doctors that, "Patient satisfaction just isn't an objective measure of care quality" (p. 616). He reminds us that doctors, who are grounded in science, value outcomes that are measurable objectively, such as disease survival. Furthermore, Mehta states that many doctors argue that patient satisfaction may measure patient expectations rather than their actual experience, and satisfaction survey results are representative of a relatively small sample of people.

In addition to the CQCO (2016) satisfaction survey results, authors such as Epstein and Street (2007) and Boissy and Gilligan (2016) emphasize how important patient-centred communication (emphasizing the patient's perspective) is to disease outcomes, and the importance of the relationship between healthcare professionals and patients to patient-centred communication. I suggest that improving the communication and teaching skills of oncology healthcare professionals would build relationships with adults with cancer that could better prepare them to cope with their illness, actively participate in decision making and manage his or her illness to the degree that he or she chooses. This suggestion is supported by the statement, "Effective communication, including active listening, expressions of empathy and sensitivity to the experience of the person affected by cancer, has been shown to improve psychological adjustment, adherence to treatment plans and satisfaction with care" (CQCO, 2016, "Why is this important," para. 2). Communication, information, and education greatly influence cancer patient experience. My study explores these interrelated factors further.

Purpose of the Study

I believe more focus is needed on learning about the cognitive and emotional needs of adults with cancer to understand how to improve their experience and satisfaction with their cancer treatment and care. As I stated in the previous section, quantitative measures of cancer patient satisfaction with their experience of care have consistently indicated an opportunity for healthcare professionals to improve their practice, yet the scores for information, education, communication, and emotional support have not improved (CQCO, 2016). Why not? Aside from the previously mentioned concerns that some doctors have regarding the appropriateness of satisfaction surveys, the literature does not explain why we are not seeing a change in these measurements. Are the right people in cancer centres involved in this discussion? Is the

quantitative tool used, a paper-based questionnaire administered by mail, really indicating a problem? Is the sensitivity of the quantitative tool used adequate to detect a change in experience? Is the questionnaire administered at the best time in their illness for an adult with cancer; is the method of administration of the survey appropriate? Does the questionnaire ask the right questions? Are there better ways to investigate the cognitive and emotional needs of adults with cancer? Perhaps quantitative tools that attempt to objectify the patient's subjective experience are not adequate to illuminate the needs of adults with cancer. I questioned whether subjective tools like qualitative inquiry could explain this more clearly.

I conducted this qualitative research study based on narrative inquiry and arts-based research to address these questions and deepen my understanding of the cognitive and emotional needs of adults with cancer. By attending to their experience stories, I hoped to elicit suggestions for improving dialogue and relationships with healthcare professionals. These findings will be shared for the benefit of adult cancer patients, healthcare professionals, and cancer educators, and to enrich the field of adult education.

Research Question

I believe that using qualitative methods to explore the experiences of adults with cancer will provide me with deeper insight into their cognitive and emotional needs. Since information, education, communication, and emotional support are essential to adult cancer patients' experience of care, and Clandinin and Connelly (2000) suggest that personal narratives have the power to make personal experience accessible to a broad audience, I gathered the experience stories of women with cancer so that I could answer this question: How do illness narratives and arts-based artifacts deepen our understanding of the cognitive and emotional needs of a cohort of adult women with cancer?

In this dissertation, I describe how I heard the cancer experience stories of a group of women and what I learned about their cognitive and emotional needs by writing about their experiences. I also demonstrate my subjective interpretation of their stories in poetry and in visual representations to illustrate and communicate what they taught me. I intend to submit abstracts to education and healthcare professional conferences, and papers to academic journals in future to present my findings. By presenting and publishing, I will have further opportunity to provide insight and suggestions that may help oncology healthcare professionals establish relationships that are more meaningful, and provide information, education, and emotional support that is more appropriate for adult cancer patients who are negotiating their diagnoses, treatments and lives with cancer. In the next chapter, I will discuss what I have learned from reviewing the literature about the adult learner, the adult learner with cancer, and the qualitative forms of inquiry that enabled me to learn more about adult cancer patients' cognitive and emotional needs.

CHAPTER TWO: REVIEW OF RELATED LITERATURE

This literature review investigates my topics of interest: (a) adult learning theories and approaches, such as andragogy and transformational learning; (b) how discourse, power, and position impact on the doctor–patient relationship; (c) forms of qualitative inquiry including narrative inquiry, arts-based artifacts, and writing and analyzing stories; (d) illness narratives; and (e) the role that narrative competence can play in interactions between doctor and patients. According to Hart (2008), by reviewing this literature I will develop an understanding of the theories involved, know what has already been researched and the methods used, and identify what remains to be investigated and understood about each topic. Exploration of these topics has deepened my understanding as I questioned my previously held beliefs and validated what I have observed in interactions between healthcare professionals and patients. I acquired new perspectives and language to describe my impressions and insights. I examined how the power structures that support the current practice and experience of medical care impact greatly on how adults learn in illness and on the formation of relationships between doctors and patients. The review begins with a discussion of the elements of adult learning, then an examination of the literature that describes how adults learn, followed by what is known about how adults with cancer learn. The chapter concludes with an overview of the qualitative forms of inquiry that are suitable for this study.

Adult Learning and the Four-Lens Model

Since adult cancer patients are suddenly immersed in a steep experiential learning curve about their disease, its treatment and their survival, it is important to begin with understanding how adults learn. Merriam and Caffarella (1999) identify three areas with which to frame adult learning theory. They describe the nature of the adult learner, the context within which adults

learn, and the learning processes that adults engage in as important components to understand adult learning. Kiely, Sandmann, and Truluck (2004) add the perspective of the educator to these three attributes to create what they describe as a four-lens model for examining and understanding adult learning. To analyze and discuss what I have discovered from the literature concerning how adults learn, how adults learn during illness, and the essential elements of the doctor–patient relationship, I will utilize the four-lens model of adult learning proposed by Kiely et al. (2004). This model provides a framework to support my discussion of the literature review. My understanding of the four-lens model is illustrated in Figure 1.

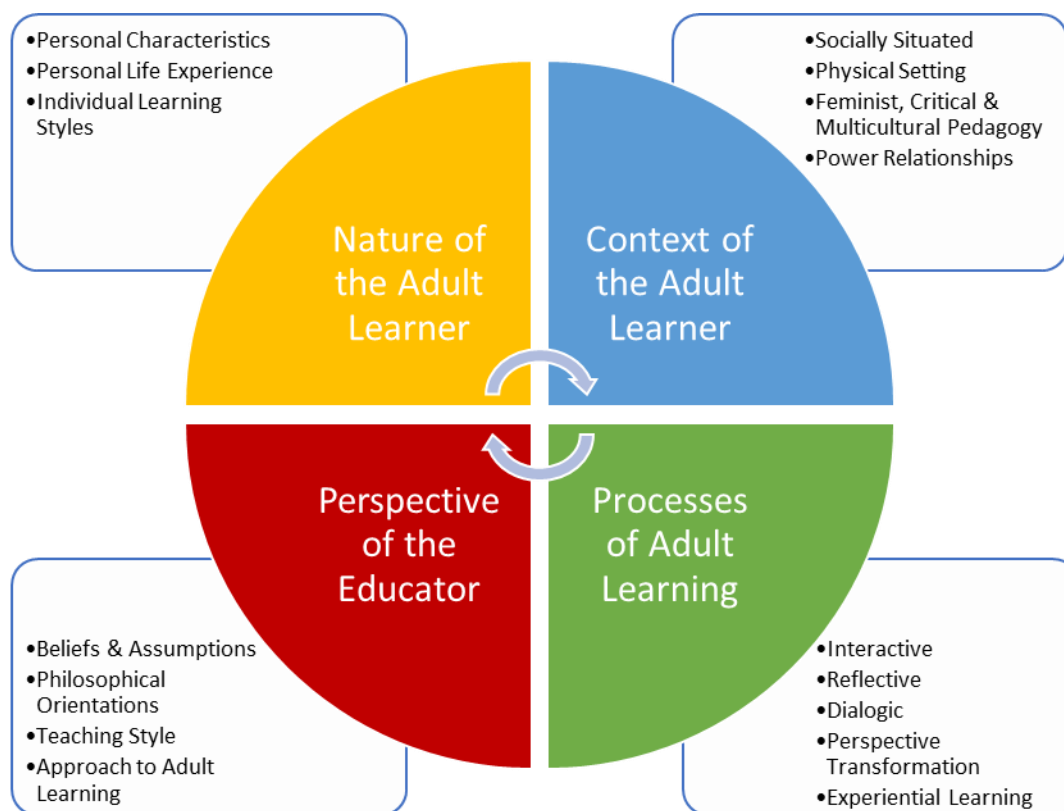


Figure 1. Graphic of the four-lens model of adult learning. Adapted from Kiely et al. (2004) by S. Boyko (2015).

The Adult Learner

I will look at the basic attributes of the adult learner that are described in the literature in more detail. In the section that follows, I will describe what the literature tells us about the attributes of adult learners with cancer to convey the uniqueness of their learning needs. Perhaps the characteristics of the adult learner, such as those described in the four-lens model, were not taken into account when the quantitative survey tool that measures patient satisfaction was developed. Figure 2 illustrates the nature of the adult learner.

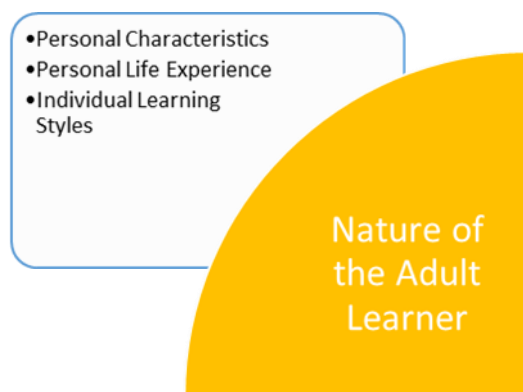


Figure 2. Graphic of the nature of the adult learner.

Nature of the adult learner. What are the characteristics of adult learners? Drawing from Andragogy—an adult learning theory, model, or approach proposed by Knowles (1980; see also Merriam, Caffarella, & Baumgartner, 2007)—adult learners are likely to be more self-directed than children or adolescents and can draw on and add to their prior knowledge and experience when learning something new. Their readiness to learn is often related to undertaking new roles and responsibilities in their lives. As well, adult learners are more apt to focus on solving problems and readily apply their new learning to their current situation and goals. Adults need to know the reasons why they are learning something new to make sense of it, and their learning is more likely to be internally motivated than curriculum driven.

Kolb (1984; see also Cranton, 2000) described four stages of experiential learning that are often used to explain how adults learn. These are: (a) our actual or concrete experience of learning something new, (b) either observing others learning something new or reflecting on our own learning experience, (c) conceptualizing and theorizing about our observations and reflections, and (d) solving problems and making decisions using our conclusions. Kolb further described the adult learner as favouring one or more stages of learning, referring to these preferences for stages of learning as learning styles. He described learners who prefer to conceptualize and experiment as convergers, those who prefer to conceptualize and reflect as assimilators, those who prefer to actively engage in the experience and experiment as accommodators, and learners who prefer to experience and reflect on their experience as divergers. While learning, adults may move between these styles, favouring one over the other according to his or her learning need and the situation in which learning occurs. Adults also may utilize different styles of communication along with their learning style. The University of Kentucky Violence Intervention and Prevention Center (n.d.) document describes the basic communication styles as passive, those who tend to avoid expressing their opinions and needs; aggressive, people who prioritize their own agendas and needs; passive-aggressive, those who combine both styles by agreeing with but not adhering to a course of action; and the assertive style, people who firmly advocate for their rights and needs while respecting the rights and needs of others.

Given the characteristics, stages, and styles of the adult learner as described, how does the diagnosis and treatment of cancer impact on the ability of an adult with cancer to learn and make decisions about treatment? If an adult has no prior knowledge or experience of cancer, how will his or her experience of learning be affected by a predisposition to be self-directed, accommodating or passive? Figure 3 illustrates the context of the adult learner.

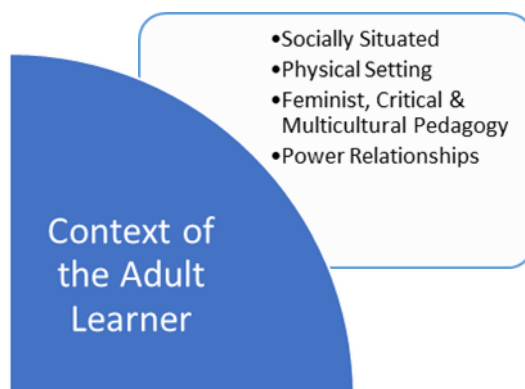


Figure 3. Graphic of the context of the adult learner.

Context of the adult learner. How does the learning environment affect adult learning?

Some of the literature I reviewed takes this question as its central focus. For many adults, learning is a social activity, whether in a classroom or a workplace. Caffarella and Merriam (2000) use “situated cognition” to describe how adults learn by their interactions with others, and in their reflection on the learning experience. Brown, Collins, and Duguid (1989) emphasize that knowledge is constructed while the adult participates in a new activity, and within the context and culture of where he or she is learning. Acknowledging the relationship of the adult learner to his or her social surroundings and physical location is paramount to understanding how adults learn. Inequities in societal power relationships may put the adult learner at a disadvantage if the inequities result in discrimination against, oppression or exclusion of the adult learner, and deny him or her equal participation and access to learning (Kiely et al., 2004). Therefore, issues of race, gender, class, ability (disability), and sexual orientation must be factored into the discussion and practice of how educators teach. Existing socioeconomic, cultural, and political structures may dominate or limit the relationships that can be formed, the kind of interactions learners may have with their educators and each other, their level of participation in education activities, and the education practices or activities available to them in the adult classroom (Fenwick, 2000).

If learning is affected by the environment in which it occurs, how does entering an unfamiliar place like a cancer clinic, and interacting with strangers like doctors and other healthcare providers (who I describe as having greater social power and a tendency to use unfamiliar language) affect how adults with cancer learn? Are they at a disadvantage because of their lack of knowledge and understanding of their disease and its treatment?

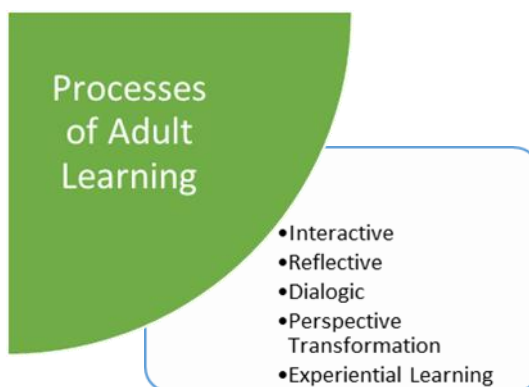


Figure 4. Graphic of the processes of adult learning.

Processes of adult learning. Figure 4 illustrates the processes of adult learning. How do adults learn? Researchers may approach adult learning from different theoretical perspectives, yet many emphasize the internal processes and the meaning-making that occurs when adults learn. Paulo Freire describes these internal processes as “consciousness-raising,” Larry Daloiz as representing “growth and development,” and Robert Boyd suggests “making the unconscious, conscious” (Dirkx, 1998). However, Mezirow’s (1981) Transformational Learning Model or learning theory is often utilized to explain how adults learn. He noted that adults change their beliefs, values, and perspectives when their reality and experience are no longer congruent. Mezirow pointed out that this transformation in perspective can be triggered by a significant or critical experience in life which causes the adult to question his or her previously held beliefs; he or she becomes more receptive to learning something new. This discordant experience, or

cognitive and emotional dissonance, is referred to as a “disorienting dilemma” (Cranton, 2000, pp. 21-22). Once faced with a crisis of disorientation, Mezirow suggested that adults enter a learning cycle where they examine their own preconceived beliefs and values more critically, explore their sense of feeling alienated from their group, engage in discourse with their peers and mentors to assess and test their assumptions, acquire new knowledge to create a plan of action, explore options for how they might take on new roles in a new paradigm, and gain confidence while they build competence in their new relationships in society.

Since I would describe adults with cancer as experiencing a disorienting dilemma, does the heightened anxiety that many people experience with illness affect how they learn? To make meaning of the new situation that the adult with cancer is presented with, does his or her receptivity to learning or ability to learn change?

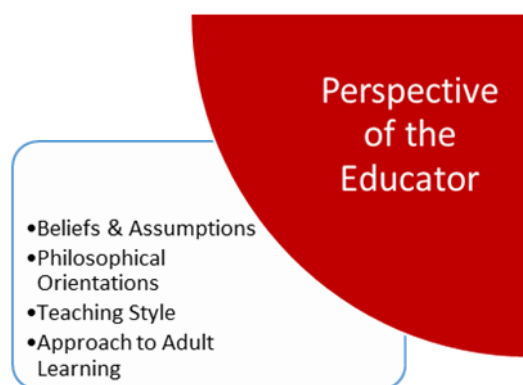


Figure 5. Graphic of the perspective of the adult educator.

Perspectives of the adult educator. Figure 5 illustrates the perspective of the adult educator. A fourth focus of study in the literature relates to how our past learning and teaching experience influence how we teach adults. Just as the adults who we teach have different reasons for being in the classroom, educators of adults come with their own preconceived notions regarding why they should teach adults (purpose), how adult learners and educators should

behave in the classroom (roles), and how they should teach adults (teaching styles or methods). They are also influenced by their prior experience in teaching, their intuition or the insights they have gained, and the practical or experiential knowledge they have acquired, as Kiely et al. (2004) suggest. Zinn (2007) asserts that if all those who are involved in teaching adults (I include doctors and other healthcare professionals as teachers of adults) were to understand the philosophical assumptions that underpin their values, beliefs, and practices, their practice of adult education would be enriched. He describes their assumptions about teaching as: (a) behaviourist (focused on shaping a desired behaviour like a professional attitude), (b) liberal (promoting content-mastery to demonstrate performance of a skill), (c) humanist (fostering personal growth and self-direction to learn), (d) progressive (emphasizing experiential learning and problem-solving skills), or (e) radical (being critical in nature and emphasizing social change) traditions.

Because the information and education that healthcare professionals provide to adults with cancer greatly impacts on their experience and learning, how do their perspectives on teaching and learning influence how they teach? If healthcare education emphasizes the behaviourist, liberal, and progressive perspectives, how does this overshadow the humanist and radical perspectives in our teaching?

The key question has emerged from this literature review that will drive this research study: What does a diagnosis of cancer bring to the experience of transformational learning? Secondary questions of interest are:

1. How does the diagnosis and treatment of cancer impact the ability of an adult to learn?
2. How does entering an unfamiliar place and interacting with unfamiliar people affect adult learning?

3. How does the heightened anxiety that many people experience during illness affect the way that they learn?
4. How do healthcare professionals' perspectives on teaching and learning influence the way that they inform adults with cancer about treatment and survival?

The four-lens model of adult learning is a helpful frame to illustrate my understanding of adult learning. Similarly, I will use these four lenses to consider the learning needs of adults with cancer in this next section.

The Adult Learner With Cancer

My understanding of the four-lens model of learning for adults with cancer is illustrated in Figure 6.

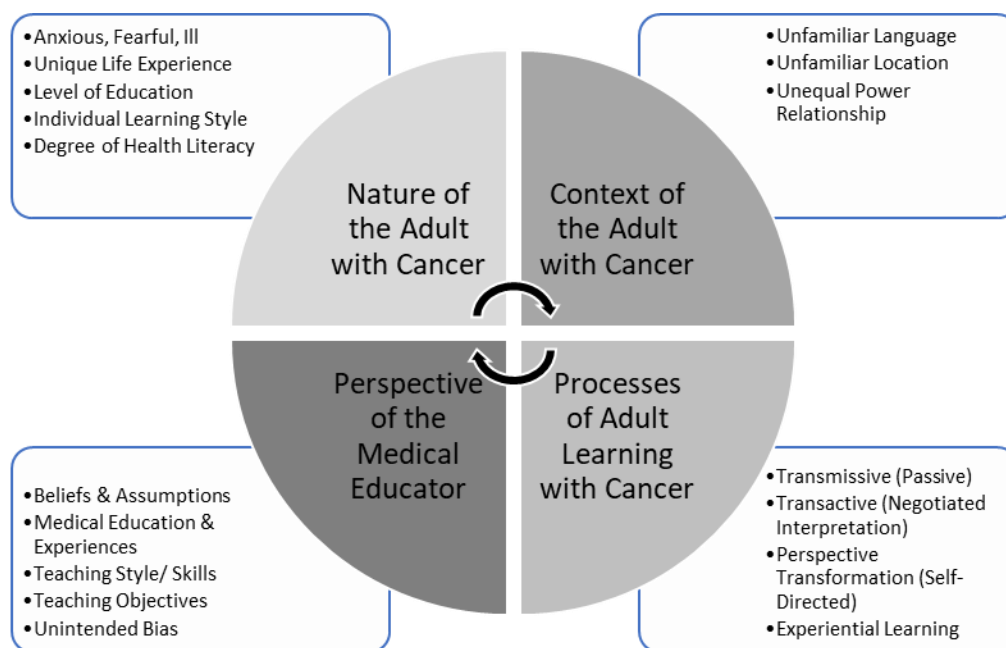


Figure 6. Graphic of the four-lens model of learning for adults with cancer. Adapted from Kiely et al. (2004) by S. Boyko (2015). The previously colourful image is now shaded in grey to reflect my perception of the impact of the cancer diagnosis on the adult learning perspective.

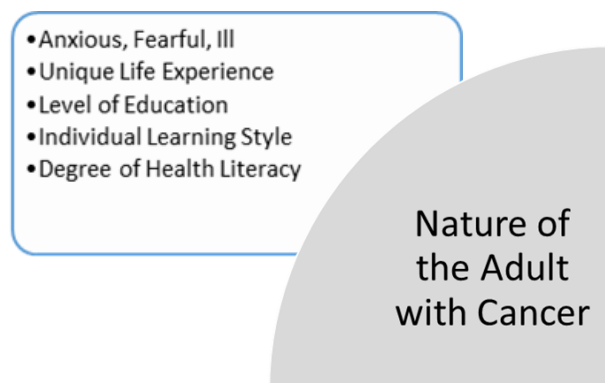


Figure 7. Graphic of the nature of the adult learner with cancer.

Nature of the adult learner with cancer. Figure 7 illustrates the nature of the adult learner with cancer. What are the characteristics of adult learners with cancer? From the previously discussed literature, we determined that adult learners tend to be self-directed, internally motivated, and focused on problem-solving, especially when they have a need to learn. The various styles of adult learning might influence a range of responses to a diagnosis of cancer. An assimilator, who tends to watch and think, may require more time to reflect on any new information they receive. A person with a convergent style prefers doing and thinking and may seek new information to solve real problems. Divergers, who watch and feel, may actively seek information by asking questions and exploring all the options. Those with an accommodating style learn by doing and feeling and may tend to rely on others for instructions without question. Responses to learning new information about cancer may be complex, difficult to predict, or reflect more than one simple profile.

In addition to possessing a variety of life experiences, and cultural, socio-economic, and educational backgrounds, adults with a diagnosis of cancer may experience fear and anxiety that may “confound and interfere with the appropriate processing of health information” (Hovey et al. 2012, p. 541). As well as fear and anxiety, he or she may also feel unwell physically and have

difficulty concentrating. This is especially concerning as the information about cancer and its treatment that is presented to newly diagnosed adults at the beginning of the cancer journey, is often very complex, contains unfamiliar terminology and is of critical importance for informed decision making about the treatment options that are being presented.

Adding to the complexity, adults have unique preferences for how they like to learn; they may prefer to receive information orally or visually, or a combination of both. He or she will vary in the amount of time needed to process the information (to discuss and reflect) and possess different levels of reading ability. Receiving new knowledge now, especially if the person does not have a previous or positive experience of cancer to relate it to, may also serve to increase the adult cancer patient's anxiety even further. The adult may not feel ready to learn and he or she may require more processing or reflection time before formulating and asking questions. As well, the information may not be presented: (a) according to his or her preferred way of learning, (b) using words that he or she understands, or (c) at his or her reading level if written information is provided. Considering the characteristics of adult learners described by Knowles (1980) and the stages of learning and learning styles of adult learners that Kolb (1984) described earlier, learning about cancer and treatment now may be challenging because of the fear and anxiety that cancer generates and the feeling of being overwhelmed with new and unfamiliar information.

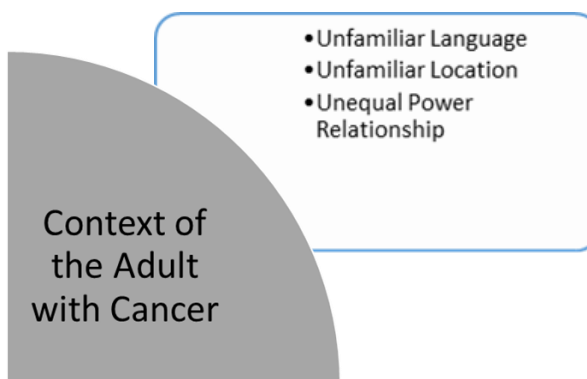


Figure 8. Graphic of the context of the adult learner with cancer.

Context of the adult learner with cancer. Figure 8 illustrates the context of the adult learner with cancer. How does the unfamiliar medical environment affect the ability of adults with cancer to learn about their illness and treatment? Adults may enter several foreign physical spaces (such as examination rooms and labs), participate in peculiar activities (such as imaging scans and invasive procedures), and meet many new people (doctors and other healthcare professionals) once they are diagnosed with cancer. The effects of the learning environment that Cafarella and Merriam (2000) described, such as interactions with others and time for reflection, and the impact of inequities in societal power on learning are especially important considerations in the unfamiliar medical environment.

As with any situated social activity, issues such as race, gender, class, ability (disability), and sexual orientation may come into play. If inequities of power between patients and professionals exist, whether these inequities are perceived by either party or not, these imbalances could accentuate these issues and affect relationships between healthcare professionals and patients, interfere with communication, education and learning, and ultimately affect the provision and experience of care. The relationship between the adult with cancer and their doctor becomes the most influential connection of their entire cancer experience because of their reliance on the doctor for informational and emotional support (Back, 2006; National Cancer Institute [NCI], 2015). To understand the learning context or situated cognition of the adult with cancer, it is essential to examine the impact of both the language used (medical discourse) and the physical space (entextualization) in the doctor–patient encounter.

Medical discourse. I have observed, personally, and professionally, that during most doctor–patient encounters, meetings that patients would not choose to have, discourse involves sharing information verbally and non-verbally. However, the doctor speaks a unique medical

language; he or she possesses specialized knowledge and the ability or power to enable or withhold treatment and information. Because of the doctor's specialized knowledge and abilities, many authors have described doctors as having greater power, authority, and status than patients. For example, Gesler (1999) emphasized the relationship between the medical language and the foreign place used on medical encounters. Kuipers (1989) described the impact of power and social control as the institutionalization or formalization of discourse in medicine. Van Dijk (1989) explained how discourse and social power is controlled in both text and talk. These authors point out that regardless of whether patients perceive doctors as having power, the doctor's knowledge, authority, and position can inhibit communication with patients and influence patients' decisions; patients may feel vulnerable, especially if they are feeling particularly unwell or frightened.

Adler, McGraw, and McKinlay (1998) further describe cancer as magnifying and refining the imbalance of power, knowledge, and authority in the doctor–patient interaction. They suggest that patients who have or gain knowledge about their diagnosis or proposed treatment can equalize the perception of a power imbalance. To facilitate adult learning now, the information presented by healthcare professionals would need to consider the characteristics, learning stages, and styles of the individual. For example, an adult who is too distressed to absorb new information might need time to reflect and to return at another time to ask questions and make decisions about care.

Turner (1990) suggests that during the medical encounter, many doctors and patients not only use essentially different languages to communicate about the reason for the visit, but sometimes have a conflicting purpose for the encounter. While an adult with cancer may be seeking information, hope, reassurance, and curative treatment, a doctor may be focused on

promoting a specific cancer treatment or an outcome other than cure, such as control or palliation (alleviating the symptoms) of their disease. An assimilator may require more time before making decisions about a plan of treatment. A person with a convergent style might prefer moving directly to action. Divergers may be prepared to ask questions and explore all options. Those with an accommodating style might accept a proposed treatment without question.

The doctor often speaks medical language, one that can be laden with specialized medical terminology, while most patients speak layperson or everyday language. Kuipers (1989) describes how medical language can be used to maintain control of the patient in the encounter by minimizing the patient's understanding and involvement in the discussion and the decision-making. This paternalistic approach, stemming from a liberalist or behaviourist orientation, may occur if the doctor believes that he or she knows what is best for the patient. Ford, Fallowfield, and Lewis (1996) describe instances where the doctor frequently interrupts the patient's story with questions, or redirects the story according to the outcome that the doctor expects for the encounter as controlling behaviours. Van Dijk (1989) explains how instructions issued by the doctor for the patient to follow can be interpreted as another way of controlling patient behaviour. Because of their objective focus on disease, many doctors are not aware of the effect of their medical language and conversational style during their encounters with patients. Education could raise doctors' awareness of these effects and perhaps encourage self-reflection on their own practice.

Doctors can also routinize the delivery of the diagnosis for consistency by revealing only part of the diagnosis, as Kuipers (1989) points out, sometimes under the assumption that patients do not need to know all the information or will not be able to understand all the information at once. Hovey et al. (2012) discuss how doctors may unconsciously impose their own values and

preferences when choosing the information to provide to the patient, rather than identifying and addressing the patient's concerns. A patient's consent for treatment must be informed by knowing the risks versus benefits of the proposed treatment; however, Beseicker (1990), Cassell (2005), and Kuipers (1989) emphasize the influence of the power and knowledge imbalance in the doctor–patient encounter. If the doctor and patient are speaking different languages (medical vs. layperson language), and if the patient feels intimidated during the encounter, we may indeed question whether consent can ever be truly informed and whether patients can really make decisions without some degree of doctor influence or suggestion.

Kuipers (1989) emphasizes how the doctor often searches for facts during the consultation to create the medical record entry, while selectively discarding other elements of the patient's story, such as the patient's interpretations, feelings, or social factors, which do not fit the template that doctors are trained to use to record and transmit the patient's story to other doctors and healthcare professionals. He further describes the patient's words as being reduced and controlled through a standard discursive formula into medical histories. If the patient's own words are used in the written history, they are framed in quotation marks to imply that the doctor cannot be held responsible for what the patient actually said. Both Brody (2004) and van Dijk (1989) explain how the doctor's story, the biomedical voice, can effectively silence the patient's story, the biopsychosocial voice, during the consultation. In this situation, where the type of information provided and the flow of conversation is directed by the doctor, adults who require time to reflect, process and understand new information may be at a disadvantage.

Entextualization: The institutionalization of discourse. Gesler (1999) refers to examining rooms that are found in doctors' offices or clinics and hospital wards, as ritual spaces where the doctor–patient interaction occurs. He describes these ritual spaces, and the practice of

requiring the patient to wear a standard hospital gown for the examination as having the impact of controlling the patient's behaviour. Gesler helps us to recall our own experience of a setting that is foreign and impersonal; an examining table that is hard and cold. Instruments used for the examination are strange to us and often cold as well. Patient gowns and drapes that are used to cover parts of their bodies barely preserve personal dignity. Patients often feel vulnerable in these settings and at a disadvantage. The setting and the trappings of the examination process reinforce the image of the doctor as the holder of special knowledge; the instruments and physical examination procedures emphasize the mystique of the practice of medicine.

As Caffarella and Merriam (2000) suggest, since adults learn by interacting with others and by reflecting on the experience, the impact of the kind of communication, or medical discourse and the location of the encounter, the entextualization, are important considerations when discussing the learning of adults with cancer. Adults with cancer do not choose to interact with strangers in an unfamiliar location, or to be confused by medical language in a situation over which they have no control.

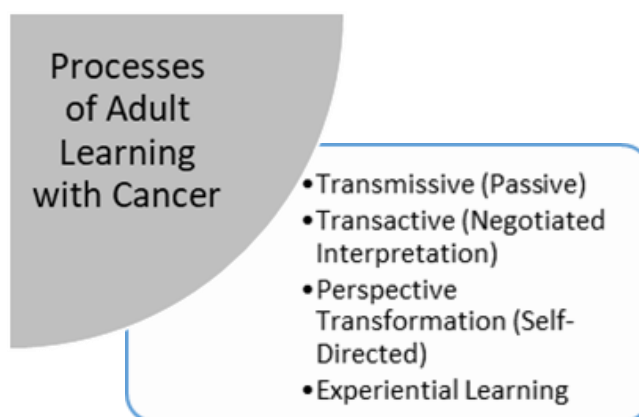


Figure 9. Graphic of the processes of adult learning with cancer.

Processes of learning when an adult has cancer. Figure 9 illustrates the processes of adult learning with cancer. How do adults with cancer learn? While each adult brings his or her

own unique perspective to every learning experience, the adult with cancer unfortunately is suddenly pressed into assuming the uninvited role of cancer patient in the unfamiliar cancer clinic. Since adults are most often self-directed learners, this loss of choice can impede learning. The disorienting dilemma of being diagnosed with cancer makes learning something new, opportunities to discuss this new learning and critical reflection on the experience, all elements of transformational learning, essential to begin to act and regain harmony in their lives.

Adults with cancer seek new information so that they can cope psychologically with their disorienting dilemma, to help manage and live with their disease and make insightful decisions. In addition to individual learning and communication styles, the cancer education literature describes their information seeking styles and behaviours. For example, Ehemann et al. (2009) described adult cancer patient information-seeking styles as being either active, moderately active, or passive. Like other authors, they found that these styles may vary by age, gender, and level of education. However, they also found that interest in information seeking varied between diagnosis and the end of treatment. Zilinski (2010) pointed out that regardless of age, gender, and education level, a high stress level at diagnosis can create active information seekers at any time.

Miller (1995) examined how adults with a cancer diagnosis monitor (actively seek) or blunt (passively avoid) potentially threatening information to cope psychologically. She asserted that while monitors (active seekers) are better informed, they tend to be more concerned and distressed, and they prefer a more passive role in decision-making. I propose that the monitoring-blunting style may vary between the time of diagnosis and end of treatment and may not always align with coping and decision-making preferences of the individual as suggested. Zilinski (2010) wisely consolidates these ideas, asserting that regardless of who is seeking what, and when, all patients want information about their cancer, when they are ready to receive it and only

as much as they want. These authors emphasize the importance of tailoring the information, and the method and timing of its presentation, according to the needs of the individual with cancer. Regardless of generalized categories, peoples' information needs vary. I suggest that the increasing accessibility of medical information on the Internet, the rapid pace of technological advances and the increasingly easy connectivity between individuals across the globe will continue to shape how adults with cancer support their own information needs, in ways that adult educators and healthcare professionals have yet to envisage. People with convergent and assimilating learning styles might be the greatest users of the Internet to support their cognitive and emotional needs.

Some people with cancer may also seek information to help them cope through cancer-related support groups. People join support groups “to learn more about their diagnosis, to share their concerns, and to compare their physical and emotional progress with other individuals” (Krizek, Roberts, Ragan, Ferrara, & Lord, 1999, p. 86). A study by Butow, Kirsten, et al. (2007) found that the top reasons for joining a group were “knowing I am not alone and hearing about current medical research” (p. 1042). Grande, Myers, and Sutton (2006) point out that relatively few patients join support groups overall, perhaps because their healthcare professionals do not endorse them; they describe those who do join groups as “more likely to be younger, more educated and utilise formal support” (p. 329). These authors agree that adults with cancer are more likely to join a support group when their needs for information and support were not being met by their doctors or at home. They also emphasize the importance of learning when an adult has cancer and the role that doctors and other healthcare professionals play not only in providing information, but also supporting information-seeking behaviours.

However, Hovey et al. (2012) use the metaphor of a “conduit” to describe how many

doctors communicate with patients during their interactions. By assuming a typical behaviourist or liberalist viewpoint, which they describe as common in medicine, doctors tend to objectify the patient. The doctor (or other healthcare professional) with the expert knowledge often approaches the interaction with the patient as an opportunity to transmit the necessary information to the passive patient without considering learners' characteristics, their readiness to learn or their learning, communication, or coping style. Although flexibility in the timing and availability of teaching and learning for adults is essential for transformational learning, since the "transmission and reception of medical information is not linear or straightforward" (Hovey et al., 2012, p. 543), the doctor, environment and healthcare system cannot always accommodate these learning needs. Often, critical information is delivered to adults with cancer at the convenience of the healthcare professional in a standard manner, using a limited number of methods such as written pamphlets and group teaching sessions, and at times that are not optimal for adult learning to maximize the time and resources available.

I assert that, unless the nature of the individual adult learner, the effects of the medical context on adult learning, and the processes of adult learning can be considered and accommodated, the learning experience of the adult with cancer during clinical encounters will remain focused on the transmission of information, and not optimize the adult's need to learn in a more subjective and transformational manner. As the literature indicates, many adults are oriented to solving their own problems, being self-directed, and desire inclusion in the decisions made about their care; these needs intensify when they have cancer. Their interactions with doctors and the medical system may be complicated by the ways that they prefer to learn and communicate. Individuals' behaviours may range from passive or assertive, dependent or self-reliant in their interactions with doctors and other healthcare professionals. Improving patient satisfaction is complicated and cannot be reduced to one model or approach to suit everyone.

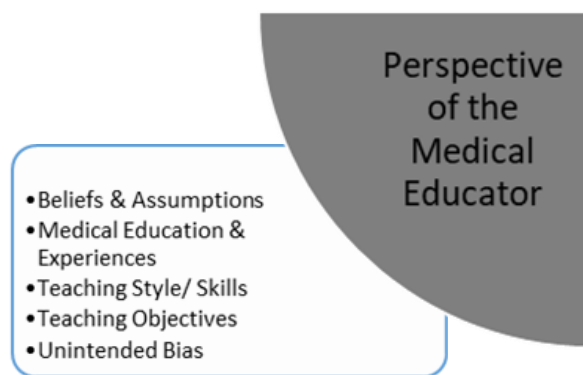


Figure 10. Graphic of the perspective of the medical educator.

Perspectives of the medical educator of adults with cancer. Figure 10 illustrates the perspective of the medical educator. How does the past learning and teaching experience of healthcare professionals in oncology influence how they teach and communicate information to adults with cancer? Younie (2014) states that many doctors and other healthcare professionals were themselves taught by means of a traditional transmissive approach to learning that emphasized learning scientific facts and methods without consideration of how they preferred to learn new information and skills. Clack, Allen, Cooper, and Head's (2004) study compared the personalities of a large cohort of doctors using the Meyers-Briggs Type Indicator (MBTI)®, a self-reported assessment of how individuals prefer to use their perception and judgment, with those reported for the general adult population in the United Kingdom (UK). They hoped to identify how doctors may differ from prospective patients, since most complaints about doctors relate to poor communication, and communication influences patient satisfaction and agreement with the plan of action. The measures pertaining to modes of perception (how they take in information and learn about things), which are considered important for effective communication, indicated that doctors differed significantly ($p < 0.001$) from the general population. Doctors were more likely to be intuitive in perception (seeing different possibilities

for the future) when compared with more than 75% of the UK population, who were more likely to be focused in the present. Clack et al. believed that this difference in perception could create difficulties in communication between doctors and patients. Within this cohort of doctors, the measure for perception was divided between intuitive (50.5%) or sensing (49.5%). These doctors also had a strong thinking (63.6%) judgement (logical analysis with a focus on objectivity) measure. I compared these combinations of perception and judgement measures, intuitive/thinking and sensing/thinking with Kolb's (1984) learning style descriptions. These doctors could be convergers (doing and thinking) or assimilators (watching and thinking) in their learning styles. Clack et al. recommended that doctors and other healthcare professionals learn how to recognize their own learning and communication preferences and those of others so that they can adjust how they communicate to better meet the needs of patients.

The medical teacher often performed the role of the expert who would transfer knowledge to the willing and passive student. Younie (2014) describes undergraduate education for many doctors as “dominated by depersonalized disease-based knowledge acquisition” (p. 163), that emphasized the process of diagnosing illness, which focuses the doctor's attention on the physical symptoms of the patient as opposed to considering the whole person. This objective focus places the values, beliefs, and practices of many doctors and other healthcare professionals within the behaviourist (focused on shaping a desired behaviour), the liberal (promoting content-mastery), and perhaps the progressive (emphasizing experiential learning and problem-solving skills) traditions as described by Zinn (2007). As a healthcare professional and medical educator, I can attest that traditionally, teaching healthcare professionals at both the undergraduate and continuing medical education levels, has rarely focused on the humanist (fostering personal growth and self-direction), or radical (being critical in nature and emphasizing social change)

perspectives. Younie (2014) defines medical education as utilizing a “traditional transmissive approach to learning” (p. 164). Because of the emphasis on transmitting medical information, most healthcare education is not transformative. My study intends to augment the understanding of a more transformative approach to healthcare professional and cancer patient education.

Most doctor–patient relationships begin with the consultation visit. Many doctors would argue that it is difficult to create the opportunity for adults with cancer to have the necessary dialogue and time for reflection to assess new information within the context of the time-limited consultation visit. However, Marvel, Epstein, Flowers, and Beckman (1999) demonstrated that soliciting the patient’s agenda or story during the consultation visit used very little extra time, ensured important information was provided and reduced the need for return visits. Although there will be variations in the length of time a patient needs to tell their story, a study by Langewitz et al. (2002) showed that 2 minutes of listening is enough time for 80% of patients to tell their stories. As Tidy (2015) reminds us, since the adult patient is the expert of his or her own health experience, how much more would we learn if we asked the adult patient to tell us his or her illness story? What is the impact on the experience of the adult with cancer when their individual characteristics, stages, and styles of learning are not accommodated?

The four lenses of adult learning—the nature of the adult learner, the context where learning occurs, the processes that support adult learning, and the perspectives of the healthcare professionals who provide information to support the adult with cancer—are essential components of learning for the adult with cancer. Since adults with a diagnosis of cancer are thrust into an unwanted, unique, and unfamiliar situation that creates anxiety and uncertainty, information, education, and communication are essential for adult cancer patients to navigate the experience of cancer. How could listening to and valuing the narratives of adults with cancer

promote development of a relationship with their healthcare professionals and transformational learning in the cancer clinic? How else might the experience of cancer care be communicated to doctors and other healthcare professionals?

Qualitative Forms of Inquiry

Chapter 1 described how the cancer system has relied on quantitative surveys to measure cancer patient satisfaction with their care experience. The first section of this chapter reviewed literature that examines how adults learn, and described how adult learning is confounded when an adult has cancer. Since this study intends to examine the usefulness of adult cancer patient narratives to enhance the quantitative data, what does the literature tell us about how qualitative methods have been used to explore personal experience?

Arts-Based Research and Arts-Informed Inquiry

For clarity, I will address the basic terminology that is used to discuss how the arts are used in inquiry. Is there a difference between the terms “arts-based” and “arts-informed” inquiry? McNiff (2008) defines art-based research as using artistic processes systematically as the “primary way of understanding and examining experience by both researchers and people that they involve in their studies” (p. 29). Since each healthcare interaction begins with an opportunity for dialogue between doctors and patients, my research process began by listening to the narratives of my participants and not with asking them to participate in other forms of creative expression. This research was not intended for art-making as McNiff suggests, however there was opportunity to incorporate both participant and researcher artistic expression in the data collection, analysis and dissemination of the findings. Cole and Knowles (2008) describe arts-informed inquiry as encompassing both “text-based means such as fiction, creative non-fiction and poetry” and “image-based approaches including painting and photography” (p. 62) to

enhance meaning-making. Rolling (2010) further expands on this distinction by suggesting that “arts-informed research isn’t necessarily focused on the arts at all, reflecting instead a researcher who has been inspired by a work of art, arts methods, or a body of work to attempt to represent their research in a novel form or format” (p. 105). The participants, through their non-fictional stories and personal artifacts, and I, the researcher, through my fictional poems and drawings, brought text and image to this inquiry. I consider art-based research as an overarching category in qualitative research. I will use the term “arts-informed inquiry” preferentially in this dissertation to reflect how I conducted this inquiry.

Cole and Knowles (2008) also state, “the research text is intended to involve the reader/audience in an active process of meaning making that is likely to have transformative potential” (p. 62). Quantitative patient satisfaction survey results have not managed to convey the necessity and urgency of improving cancer patients’ experience of care to doctors and other healthcare professionals. If adults are motivated to learn when confronted with a disorienting dilemma, then how could this provide the conditions for doctors to be receptive to the stories of adults with cancer? Since doctors tend to not value patient satisfaction survey results as stated in Chapter 1, how can cancer educators, if it is possible, create a disorienting dilemma for doctors? Skop (2016) suggests that art can move beyond “the limitations of words by offering alternative forms of communication to convey the depth and complexity of embodied experiences and emotions” (p. 29). Thus, art has the potential to create a disorienting dilemma by involving the audience in making an emotional connection. This dissertation explores how the arts can do this.

The arts can also communicate the experience of adults with cancer to very broad audiences effectively. For example, Gray, Fitch, Labrecque, and Greenberg (2003) and Nisker (2008) used the medium of theatre to convey meaning from the stories of their research

participants. Gray et al. (2003) translated the experiences of men with prostate cancer and their spouses into a dramatic production to create a vehicle that would have greater emotional impact on medical, patient and family audiences than text alone. Nisker (2008) conveyed the concerns of a woman with breast cancer about her difficulty accessing genetic counseling through a powerful and emotionally moving two-person play to raise awareness of this issue. How we understand each other is enhanced by hearing and telling our stories. Next, the use of narratives in making meaning, healing, communication, and research as a form of arts-based inquiry will be explored.

Narratives: Purpose and Significance

Why use stories or narratives for data collection and analysis? This literature focuses on how stories can be used for making meaning, improving communication, promoting healing, and gaining deeper understandings of experience. For these reasons, narratives will be used as a qualitative way of enhancing patient satisfaction knowledge.

Telling stories. Storytelling and the oral tradition have an important place with all cultures of the world. Before there was the written word, there was the oral story, an important way of passing knowledge and traditions to other members of the community and to the next generation. Through stories, people make sense of their experience. The act of telling an oral story involves additional ways of communicating; tone and volume of voice, facial expression, gestures and body language. Egan (1992) emphasizes that “Stories and images also have the power to engage the emotional commitment of their hearers to the content represented” (p. 642). Stories are more than communication; they are an invitation to sharing the experience of the teller. Since stories have the power to connect people on a personal level, perhaps they can serve to enhance doctor–patient relationships.

Stories also help us make meaning. Narratives are stories that we tell about events in our lives. Bruner (1991) argues that the ability to understand narrative is one of the earliest abilities in children and is “among the most widely used forms of organizing human experience” (p. 9). The story elements such as the characters, setting, plot and resolution, and their relationship to the entire story, are essential to understanding the impact of these events and actions on the teller of the story.

Stories help us to relate and communicate. Charon (2001) explains how we use our narrative knowledge, our ability to make sense of stories, to understand the experiences of the person who tells the story. She describes the interaction between the teller and the listener as a “narrative discourse” (p. 1898). Clandinin and Connelly (2000) describe narrative as “the best way of representing and understanding experience” (p. 18). Familiar, respected, and easily accessible, the importance of telling and hearing stories is well understood by most people across most cultures. Stories told to share and understand experience are the foundation of disciplines of study such as anthropology, sociology, philosophy, psychology, feminism, education, and medicine. These authors agree that constructing, sharing and hearing narrative are essential to understanding our own experiences as well as the experiences of others.

Illness narratives: The healing power of stories. Creating an illness autobiographical story can be part of a sick person’s healing process. Colyer (1996) points out that there can be catharsis and validation for the person telling the story, identification and restoration of the self, and transformation of his or her role and body image. As the story is told and retold, the process of formulating and telling the story can help to unravel the meaning of this experience, add new insights and allow the teller to examine his or her self. Others who hear the story may identify with similar experiences and know that they are not alone. For example, illness stories such as

that of Dr. J. Nielsen (2001), a physician who diagnosed and treated her own breast cancer while stationed at the South Pole, are often shared publicly as testimonials and to inspire hope in other cancer patients. There are benefits for both the person telling the illness story and other sick people who hear it.

Colyer (1996) describes how illness narratives or stories have proven to be valuable in learning about the relationship between doctors and patients. She explored the stories of three women who experienced a loss of identity through their cancers. Their experience pointed to the inadequacy of physicians attending only to the physical body and suggests that a more holistic approach such as listening to patient stories is essential to address the needs of cancer patients. Charon (2001) asserts that since the time available for clinical conversations is limited, physicians need effective methods, such as encouraging the patient to tell his or her illness story by questioning and listening attentively, to build relationships. Obtained in the context of the clinical encounter, she asserts that the illness narrative can more fully inform the doctor regarding the nature and the impact of the illness on the patient, than by the doctor asking questions alone. These authors describe an example of the negative impact to the patient's experience when his or her story is not elicited, and how hearing illness stories can benefit clinical encounters.

Illness stories have been shared with healthcare and education researchers and re-presented in research reports (e.g., Charmaz, 1999; Colyer, 1996; Frank, 1998; Little, Paul, Jordens, & Sayers, 2000); in textbooks (e.g., Abel & Subramanian, 2008; Hurwitz, Greenhalgh, & Skultans, 2004); as visual creations (e.g., Lidzey, Petrone, Sanders, & Bolton, 2008); and theatrical presentations such as plays (e.g., Gray et al., 2003; Nisker, 2008). As these researchers attest, reading, hearing, seeing, and witnessing the illness story can provide doctors, researchers,

healthcare students, and other patients with a deeper understanding of how others experience illness. Gray et al. (2003) acknowledge the objectivity of medicine by stating that the illness story can also humanize “interactions in the often-dehumanizing context of modern clinical practice” (p. 228).

Further to the impact of medical discourse and the benefits of illness narratives, what do cancer patients tell us about their need to have a voice and a role in self-determination? Greenhalgh and Hurwitz (1998) emphasized the importance of the dialogue between doctor and patient to cancer patients in illness. They pointed out how dialogue is essential to form the relationship between the doctor and patient. Charmaz (1999) described how telling a story of experiencing his or her chronic illness is related to the patient’s ability to construct an image of self, and Colyer (1996) expands on this process by explaining the loss of identity that people experience with cancer, and the importance of storytelling to reclaim their own identity. Charmaz and Colyer both emphasize the importance of the dialogic connection between creating identity and telling stories. Abel and Subramanian (2008) investigated societies’ preference for hearing only positive breast cancer stories by listening to the breast cancer stories of survivors. They reported that cancer patients often feel pressured to tell only positive stories, and not to emphasize elements of their own suffering. Yet, as these survivors attest, there are experience stories of cancer that are not positive. Narrative methods of inquiry have the potential to uncover these stories. These authors all emphasize the importance of telling their stories to patients’ well-being, describe society’s influence on stories, and the doctors’ role in listening to and witnessing patient stories.

Authors and cancer survivors speaking from their perspectives emphasize similar themes. Broom (2001) explored the societal conventions that silence breast cancer patients, Ehrenreich

(2001) displayed resistance to displacing her identity with the stereotype of a breast cancer patient, and Segal (2007) elaborated how socially acceptable, or positive, stories suppress or displace other stories. Frank (1998) described how patients and doctors can enter relationships based on storytelling. Using their patient voices, these authors attest to how it feels to lose their voice by societal expectations or to be misrepresented, and support the need for cancer patients to tell their stories and be heard by doctors.

This literature demonstrates how telling stories or narratives is important to patient well-being and how hearing stories is an accessible way to understand the experience of adults with cancer. Why are illness stories, the foundation for the clinical encounter, not being told? How can I encourage doctors and other healthcare professionals to hear and value these stories? It appears that it has not been enough to simply publish illness stories or research studies. The conversation will now shift from the literature that focuses on the storyteller to the literature that focuses on the “receiver” of the story.

Narrative competence. Charon (2001) states that the practice of medicine “requires the engagement of one person with another and realizes that authentic engagement is transformative for all participants” (p. 1898). I agree that the acts of telling and hearing an illness story can create a relationship between the participants. I define narrative competence in medicine as the ability to hear, understand, and act based on hearing the patient’s story. A doctor demonstrates that he or she has narrative competence by listening to the patient to understand the meaning of the patient’s illness and expectations through the patient’s words, gestures, silences, and the type of illness story told. The doctor acknowledges the patient through actively listening and offering appropriate responses, understands and treats the medical problem, and becomes part of the patient’s illness narrative in future telling. The narrative provides more than the facts of the

illness; it can also provide the patient's expectations for the encounter, the impact of his or her current lifeworld on the illness, and where he or she is on the illness journey. By listening to the patient's narrative, doctors could also learn more about how a patient prefers to learn new information and how they like to communicate.

Narrative competence demands more of the doctor than the appearance of listening. Narrative competence requires that the doctor and patient enter a relationship where the patient has the opportunity to tell his or her illness narrative, the doctor has the opportunity to develop a deeper understanding of an individual patient's illness experience story, and that the doctor acts upon that story according to the patients' questions, fears, and expectations in a partnership of care. It is in the act of being heard and acknowledged that the adult with cancer can begin to acquire and process the information he or she needs to learn about being a cancer patient. Reflection on the new knowledge and an opportunity for dialogue can follow, which are essential elements of learning that is transformative. I assert that narrative competency is an essential skill for doctors and other healthcare professionals to possess to support adults with cancer and provide care that is patient-centred, centred on the needs of patients, instead of centred on the needs of healthcare professionals and clinic processes.

Medical education. What does the literature tell us about possible interventions to change the doctor–patient interaction in the cancer encounter? Many interventions that have been investigated and reported in the literature by researchers from Australia, Canada, the Netherlands, and the United States of America have centred on improving the communication skills of doctors by focusing on different aspects of the doctor–patient encounter. For example, Baile et al. (2000) pioneered a protocol to teach medical students how to break bad news to patients, Cordella (2004) examined the communication between doctors and patients in depth

using discourse analysis to identify how doctors unknowingly limit the patient's storytelling, and Ong, Visser, Lammes, and de Haes, (2000) investigated the effect of communication skills training for doctors on patients' quality of life.

These researchers measured different aspects of training doctors to enhance their communication skills quantitatively, to see whether these techniques increased patients' adherence to the doctor's instructions and patients' satisfaction with the encounter. Alelwani and Ahmed (2014) point out that for most studies of doctor communication skills training, medical participants demonstrate the desired communication techniques while observed and patient participants report more adherence to the doctor's instructions and satisfaction with the interaction. However, they pointed out that because there was no reported follow-up to these studies, we do not know whether participants continued to use these techniques after the study was completed and whether they were able to use these techniques effectively over time. We also do not know whether the clinics or hospitals involved in these studies changed their processes to facilitate continued use of these communication techniques. Some medical schools have incorporated communication techniques like the protocol pioneered by Baile et al. (2000) into curricula, however Jacques et al. (2011) point to the importance of continuously using these techniques in the clinic to sustain an improved clinical practice.

Jones et al. (2011) evaluated a patient education skills course that taught healthcare professionals how to identify patient learning and communication styles and how to adjust their own teaching and way of communicating to each style in role-playing situations using standardized patients (specially trained actors). The participants (primarily nurses and radiation therapy students) in multiple sites reported satisfaction with the training, found it to be relevant to their practice and requested opportunities to repeat the training again in future to refresh their

skills. It is not known whether the participants had additional opportunities to practice their skills, whether patients reported increased satisfaction in their encounters with these professionals after the course or if the professionals continued to use these techniques effectively over time.

The Royal College of Physicians and Surgeons of Canada (RCPSC), which regulates the education of medical specialists, such as oncologists and surgeons in both undergraduate medical education and continuing professional education, has defined national standards for the education, assessment and certification of doctors in Canada. The Draft CanMEDS 2015 Physician Competency Framework (Neville et al., 2015) clearly delineates the role of “Communicator” as an expectation for new doctors. Doctors are expected to “communicate using a patient-centred approach that encourages patient trust and autonomy and is characterized by empathy, respect, and compassion” (p. 5). The national standards do not address the role of the doctor as a patient teacher but specify that doctors must communicate in a way that focuses on the patient’s perspective and emphasize displaying empathy and demonstrating respectful and compassionate actions. The College of Family Physicians of Canada’s Working Group on Curriculum Review (2011) has established similar standards for the training, certification, and continuing education of family physicians that also specify the role of “Communicator” as an expectation. Developing these communication competencies as medical students will positively influence the practice of new doctors. What can we offer doctors currently in practice, whose training predates competencies such as these or who have trained in other countries and who may not have had the same emphasis on communication skills and building a relationship with patients in his or her basic medical education? The key to reaching these individuals may be through continuing professional medical education.

Patient education. The literature also demonstrates that adult education researchers have taken many approaches to preparing adults for the new role of cancer patient, at a time when they have even greater internal motivation for learning to solve their immediate problems. The adult tendency to be self-directed, draw on prior knowledge, and their need to know why they are learning something new can be maximized at this time. Adler et al. (1998) and Beseicker (1990) describe the information-seeking behaviours of cancer patients, such as performing prior research, developing questions, direct questioning of doctors, interrupting doctors, and demonstrating assertiveness. When patients were coached to employ these active behaviours prior to their consultation visits, regardless of their learning or communication styles, these behaviours positively influenced the exchange of information during the doctor–patient encounter. Several other education interventions for cancer patients have also focused on encouraging patients to develop these skills. These interventions begin to address the issues surrounding the context of the adult learner but do not necessarily accommodate the individual cancer patient’s nature or his or her process of learning.

For example, Butow, Devine, et al. (2004) evaluated the use of a cancer consultation preparation package designed to facilitate greater patient involvement during the consultation. While the package appeared to increase active patient information-seeking behaviours during the encounter, patients reported less satisfaction with their degree of involvement in decision making. The researchers speculated that the education provided raised patient expectations regarding their involvement in decision making. Patients who received the training believed that the doctor made the decision about treatment for them. The researchers concluded that providing education to change the behaviour of patients without providing similar education for doctors to be more receptive to patient involvement was not enough to increase patient satisfaction with

their degree of involvement in decision making. I suggest that change must come not only from the perspective of both the doctor and the patient, but also influence governmental, institutional, educational, and medical cultural change.

Interventions that educate doctors and patients regarding how to communicate more effectively during the doctor–patient encounter may be an important first step in changing the relationship. However, Gray et al. (2003) assert that “the element of human connection is critical for motivating health professionals to engage compassionately with patients in their care” (p. 228). They encourage educators to go beyond merely enhancing communication skills of healthcare professionals. The fundamental imbalance of knowledge and power underlying the doctor–patient relationship must be acknowledged no matter which educational interventions are applied. I agree with Rita Charon (2001) who suggests that narrative medicine, where doctors listen to and understand the stories of patients, can be the “bridge to empathetic, reflective, professional and trustworthy care” (p. 1897). Listening is the key to understanding and forming a relationship between doctors and patients.

What can the process of telling a personal narrative offer the adult with cancer? Personal narratives are how we know ourselves. Constructing and telling an illness narrative can provide the adult with cancer with an opportunity to reflect, reorganize perspectives, and regain a sense of control at a time when he or she may feel that life events are spiraling out of control. Our relationships with others, such as our healthcare providers, can help us to create and tell narratives through the processes of dialogue and reflection (Charon, 2001; Wasserman, 2011).

The provision of cancer education is not a new endeavour. Healthcare and cancer educators already design education programs for cancer patients, doctors, and other healthcare professionals. They may conduct learning needs assessments and course evaluations. Much of

the research that has been reported centres on improving the communication skills of doctors, increasing the information seeking behaviours of patients and addressing the influence of the learning context. As Kumagai (2008) and Phillipi (2010) attest, patient education often occurs in examination rooms, interview rooms or group classrooms, is transmissive in nature and relies heavily on brief oral instruction and generic written information that is explanatory or prescriptive. Delivering information in this way does not address the nature or the processes of the adult learner by providing the right information, for the right person, in the right way, or at the right time.

Narrative Inquiry

What does the literature tell us about using illness stories as a form of inquiry? Narrative inquiry, a form of arts-based inquiry, is “the study of experience as story” (Clandinin & Huber, 2010, p. 3). Clandinin and Connelly (2000) emphasize that narrative inquiry is a “collaboration between researcher and participants, over time, in a place or series of places, and in social interaction with milieus” (p. 20). They point to the relationship that develops during the collaboration between researcher and participants over the course of several meetings and perhaps in several places.

Narrative inquiry uses the information collected, such as stories, autobiography, journals, field notes, letters, conversations, interviews, family stories, photos (and other artifacts), and life experience, as the data and the means of analysis to understand how people create meaning in their lives (Clandinin & Connelly, 2000). The research text or resulting story that the researcher creates from all these sources of data reflects the researcher’s interpretation in a narrative or re-storied form. Often these data are interpreted through the perspective of the research question.

Narrative inquiry has been used in various ways to understand illness experience. For

example, Brooks and Edwards (1997) used narratives in collaboration with their ten participants to investigate women's development of sexual identity by constructing alternative (to dominant mainstream interpretations) narratives of transformation. Lee (2001) used narratives to describe how cancer affected the development of a young adult cancer survivor. Wasserman (2011) investigated how a diagnosis of cancer or a shift in health narrative presented the opportunity for personal growth for ten people. These authors used the narratives of people across a variety of life stages to describe how their participants underwent transformation or growth through their experiences. This literature supports my intention to use narrative inquiry to gain a deeper understanding of the cognitive and emotional needs of adults with cancer.

Arts-Informed Narrative Inquiry

When does a narrative inquiry become arts-informed? Artifacts and other forms of artistic expression can be used to both analyze and enhance experience in the narratives, as well as to present findings. They can also serve to engage the reader/audience in an emotional experience. Clandinin and Huber (2010) describe how “metaphors, visual and textual collages, found poetry, word images and photographs” can be used in the created narratives to demonstrate the “complex and multi-layered storied nature of experience” (p. 13) that individuals possess. De Mello (2007) states that when visual and textual images are used as “part of the analysis, during the transition from field texts to research texts, as a way of informing the meaning made” the narrative inquiry becomes arts-informed, thus creating “conditions for the readers to live an aesthetic experience” (pp. 214-215).

Poetry. Why use poetry in inquiry? Butler-Kisber (2010) suggests that poetry “appeals to our senses and opens up our hearts and ears to different ways of seeing and knowing” (p. 82). She describes poetry as effective in conveying experience by inviting emotional responses and

allowing “silenced voices/stories to be heard” (p. 83). Leggo (2008) uses poetry to “experiment with language, to create, to know, to engage creatively and imaginatively with experience” so that he can “construct understanding” (pp. 165-166). Using poetry to both analyze and communicate research findings could expand beyond what is known quantitatively about adult cancer patient experience and touch readers/audiences more deeply.

Guiney Yallop (2014) explained how he uses poetry to make sense of and communicate his own relationships with medical practitioners. He offers his stories and poems as “gifts of gratitude, as hope for healthcare and, in some cases, as admonitions to attend for all who work in, makes policy for and/or care about the practice of medicine” (p. 141). Guiney Yallop recounts both positive and painful experiences through his stories and poems, calling these his “healing journeys” (p. 142). Kendall and Murray (2004) used poetry to transcribe interviews with heart failure patients. They felt that the accounts naturally fell into stanzas built around events or people, reflecting natural breathing patterns. Creating poetry “opened up different processes of interpretive thinking, and issues of re-presentation and voice in the research process” (Kendall & Murray, 2004, p. 70). The researchers could make new connections through the process of poetic transcription and presented their findings as poetry in the hope that doctors might gain a new, more holistic perspective towards their patients.

Prendergast, Gouzouasis, Leggo, and Irwin (2009) described how poetry, specifically the concise haiku form, was used to capture the “depth and intensity of emotions, engagement and transformative affects” of music programs for adolescents (p. 311). Their haiku demonstrated how important music was to the young people who participated in these programs. By using the traditional form of three lines of “5-7-5” syllables per line, and juxtaposition of central concepts, each haiku captured and conveyed the immediate experience of participants. The haiku packed a

great deal of meaning into a small, prescribed form that focused on presenting important findings by reducing distracting information.

List or Catalogue poems are used to represent a sequence or hierarchy of concepts in richly detailed language. Franco (2005) describes list poems as lists or inventories of things, events, thoughts or feelings, centred on a theme or purpose. The List poem can also be used to tell a story. The list should be “resonant and compelling, driving the reader through the poem” (Colorado Humanities, 2017, para. 1). Sentences and grammatical structures are repeated and concepts are presented in an order that creates a sense of movement or progression, to convey meaning. These literatures demonstrate how poetic forms of interpretation and representation can create an emotional connection with the reader/audience of illness stories to convey the participants’ experiences with more intensity.

Visual arts. Allen (2014) described how art-making such as drawing, painting, collage, sculpture, writing and photography has been used to help medical students learn to observe and represent the impact of illness on the individual. Her role as artist-in-residence in a medical school pilot project was designed to foster “(re)presentation of the human body as the object of disease diagnosis and narrator of illness experience, drawing attention to modern bioethics and the (in)humane aspects of modern medicine” (p. 83), to expose the objective nature of current medical practices. The purpose of the project was to encourage medical students to express emotion to encourage a more humane practice of medicine. In 2011, Jay photographed the surgical scars of young women with breast cancer for “The SCAR Project: Breast Cancer Is not a Pink Ribbon,” which intended to not only raise awareness of the impact of the disease on younger women but also to invite the observer to focus on the “human condition itself; the images transcend the disease, illuminating the scars that unite us all” (para. 3). The images are

available on the Internet to a broad public audience. The images, particularly those taken in black and white format, dramatically highlight the women's scarred chests, a visible symbol of the impact of their experience. Israeli (2011), a breast cancer reconstruction surgeon and sculptor, created plaster casts of the torsos of six of his patients after mastectomy and/or reconstruction surgery to help newly diagnosed women make a decision about the reconstruction procedure and to offer hope. He described the patient-focused project as a visual and supportive way to address the emotional needs of women as they decided whether to undergo additional breast reconstruction after mastectomy. The visual arts are being used by artists, photographers, and doctors to (a) teach medical students to be more subjective and humanistic in interpreting their observations and to recognize emotions in themselves and others, (b) raise the general public's awareness of the impact of cancer and its treatment, and (c) as an aid to support patient decision making.

Writing narratives of experience. The performance of arts-informed narrative research requires the researcher to listen closely and tell a compelling story. As a healthcare professional, I possess active listening (I focus all my senses on the person speaking) and objective report writing skills. However, I quickly realized that I would need to expand my ability to write from the first-person perspective, if I were to convey the women's experience authentically and emotively. As Burns (2003) suggests, I would need to "show" the reader (let the reader see what is happening) rather than just "tell" the reader what to think and feel. I reviewed the basic elements of story structure as described by Lewitt (2012) and Zinsser (2001), Safi's (2016) recommendations for writing cancer stories, and Burns' (2003) creative writing guidelines to prepare for writing the women's individual narratives and this dissertation. By being attentive to the elements of story structure, writing from the first-person perspective, using descriptive and

active language, and being faithful to the facts of the women's medical experience, I strived to surpass my objective writing skills.

Unity, simplicity, and audience. Zinsser (2001) emphasizes the importance of creating unity in the story by introducing relatively few characters, making sure that the plot evolves over a short period and that the action occurs in one place. He also recommends simplicity in the language used, while keeping the audience you are writing for in mind. For example, Safi (2016) and other medical writers stress the importance of accurate scientific details, such as symptoms, treatments, and side effects, when writing cancer stories for a medical audience.

Plot, character, setting, and theme. The story sequence should consider the plot to introduce the characters and the setting, introducing conflict that is either external or internal to the central character to move the story forward, rising action of the story where various problems arise, climax or peak of the conflict, falling action, which results from the climax and describes the effects on the characters, the setting and proceeding events, and a conclusion that describes the events that follow the climax. The stories that people with cancer tell may contain several stories or plots as the disease can span a long period.

Essential to the story are the characters such as the protagonist, or main character, the antagonist, who conflicts with the main character, and minor characters. The characters can be static (their behaviour remains the same), dynamic (they experience a change in attitude and behaviours), flat (they exhibit one, or two, character traits), or round (they are complex and unpredictable). The setting, the time, and place in which the story occurs should be described in detail. The theme or the point about human life that is being made may be positive, negative, or contain a moral. The story can be written from the perspective of the first person to show a single point of view or in the third person by a someone who is not a character in the story but is

narrating from an observer's viewpoint as Lewitt (2012) describes. For example, case studies used for teaching medical and other healthcare professional students are often written in the third person. The Wisconsin Cancer Pain Initiative (n.d.) document, *Case Studies—Home Health*, provides typical examples of objective third-person narration in medicine.

Burns (2003) recommends writing vividly to draw the reader's attention to the story. To let the reader "see" the story, he suggests using strong verbs, describing the characters' reactions, using well-placed details to animate the people, and settings and expressive dialogue to show the characters' attitudes and emotions. Writing vividly about the experiences of adults with cancer would not only strongly differentiate these stories from the objective, third-person narration commonly used in medical education and practice, but also serve to convey how the adult feels. Cancer stories involve a compelling plot, dynamic characters, a conflict that arises in the form of illness, a climax or illness crisis and a conclusion or some form of resolution of the immediate health crisis. Within these stories, I anticipated learning about both positive and negative elements of adult cancer patient experiences.

Embodied knowing and body-mapping. Like the experience of telling a story, processes such as art, theatre, music, and dance can allow us to become aware of and express what we have experienced but perhaps have not yet realized. Similarly, a body map, an arts-based way of knowing, is a visual representation of a person's psychological or somatic (body) experience (or trauma); it is a way to "make visible that which ordinarily is invisible to others, and sometimes, invisible to themselves" (McLay, 2006, p. 30). In this way, body maps can represent a knowledge that is truly embodied, known or experienced in the individual, like their illness story. Body maps can be life-sized tracings of the participant or smaller representations that the participant adorns with symbols to represent their physical and psychological experience.

Body mapping has been used as a creative therapeutic tool, as a research methodology, as a form of education and to advance population health. This technique was first used by Jane Solomon in 2008 as a therapeutic workshop tool to promote HIV literacy with women in Africa. When used as a form of psychotherapy, Lidzey et al. (2008) recounted the process of facilitating palliative cancer patients to create life-sized body maps that helped them to explore particular aspects of their lives with a trained art therapist. As research, Gastaldo, Magalhães, Carrasco, and Davy (2012) used body mapping to explore the experiences of undocumented migrant workers, a marginalized and invisible group. The process allowed each worker a means to express experiences that had not been previously collected and shared with others. Skop (2016) investigated the experience of adults with fibromyalgia with body-mapping; she found that body-mapping was a suitable way to “represent people’s identities within their social contexts” because it can blend the mind, body and social contexts holistically (p. 29).

De Jager, Tewson, Ludlow, and Boydell (2016) also describe the role of visual or embodied methods such as body-mapping as a knowledge translation strategy. While participants can contribute to producing research knowledge, de Jager et al. (2016) emphasize that using the highly visual body-map for dissemination allows the research findings to be “more accessible to the broader community, outside of academia” (p. 5). Art-based methods, such as body-mapping, can also be applied as a way of communicating data that has been collected by interview.

As a form of education and a means to advance population health, MacGregor and Mills, (2011) used the results of a body-mapping exercise with women with AIDS as a form of education and then, to create political pressure on the South African government to provide anti-retroviral medication to the general population. These literatures demonstrate that body-mapping is a powerful and versatile tool for expressing the embodied physical and psychological

experience of silenced individuals. What more could body mapping elicit about the cognitive and emotional needs of adults with cancer that might enhance their experience stories and convey additional information to the healthcare team?

Addressing Gaps in the Literature

By reviewing the literature, I learned that illness narratives are being used to explore the experiences of adults with cancer to communicate their experiences to healthcare professionals and patient and family audiences. I also learned how researchers are using poetry, drama, and visual art-making like body-mapping to enhance individuals' stories of experience in research reports. I did not find studies that used illness narratives and arts-based artifacts to explore the experiences of adults with cancer to address the nature and processes of how adults learn. Patient education researchers were more likely to focus on presenting health information in different transmissional ways and evaluating whether there were immediate changes in patient behaviour quantitatively, than whether the learning was transformative for the patient (e.g., Adler et al., 1998; Beseicker, 1990). They were also interested in providing and evaluating communication skills training for doctors currently in practice but could not demonstrate sustainable changes that benefit patient learning and experience (e.g., Baile et al., 2000; Ong et al., 2000). Although the literature demonstrates a growing interest in illness narratives, and the field of narrative medicine is gaining momentum (Charon, 2001, 2007), I did not find research that explored how healthcare professionals could facilitate the transformational learning process for (and with) cancer patients using illness narratives in a way that is more qualitative, humanistic and radical in perspective.

By gathering adult cancer patient experience narratives, I hope to gain a deeper understanding of their cognitive and emotional needs as transformational learners. These narratives are intended to provide me with greater insight into adult cancer patient learning that I

intend to use to (a) guide healthcare educators who design adult cancer education, (b) assist doctors and other healthcare professionals as they develop a clinical relationship and provide adults with information about cancer, and (c) support adults with cancer who would like to be a partner in their own care.

In this chapter, I reviewed the literature that discusses adult learners, adult learners with cancer, and arts-based forms of inquiry such as narratives, illness narratives, narrative competence, narrative inquiry, arts-informed narrative inquiry, embodied knowing, and writing narratives of experience. This process has given me a better understanding of how to structure my research study and confirmed the effectiveness of using arts-informed narrative inquiry to address my research question. It has also triggered new questions:

1. How much more would we learn if we asked the adult with cancer to tell us his or her illness story?
2. What is the impact on the experience of the adult with cancer when their individual characteristics, stages, and styles of learning are not accommodated?
3. How could listening to and valuing the narratives of adults with cancer promote development of a relationship with their healthcare professionals and transformational learning in the cancer clinic?
4. How can interactions between doctors and patients change from objective, behavioural, and focused on transmission of information, to subjective, humanistic, radical, and empathetic?
5. How else might we communicate the experience of cancer care to doctors and other healthcare professionals?

From this review of the current literature on adult learners, is it reasonable to infer similar

learning and communication attributes for adult learners with cancer, such as being self-directed, problem-solvers who are internally motivated? Will participants in this study demonstrate similar preferences for how they learn and communicate? If so, how might this inform doctor and other healthcare professional interactions with patients that are more humanistic and radical in nature? Likewise, the literature on arts-based and arts-informed inquiry provides positive evidence that these qualitative methods could be adapted to examine and unravel the subjective and complex experiences of adults with cancer. Not only do patients' stories have healing power that could be transformational for both the person telling the story and those who witness it, these other forms of artistic expression such as poetry, personal artifacts, body maps, and dramatization promise to elicit an emotional response from the audience. These stories and artful items may reveal negative elements of experience as well as positive. If this is the case, perhaps the arts-based approach of this research study could be used to effect a significant change in patients' satisfaction and their corresponding quantitative survey results. The literature reviewed provides hope and inspiration for reimagining cancer education practices.

CHAPTER THREE: METHODOLOGY AND RESEARCH DESIGN

Since I wanted to understand the meaning that each adult with cancer assigned to their experiences, I approached the work qualitatively because “qualitative methods are uniquely capable of exploring the meanings which individuals confer on events or life experiences” (Kumagai, 2008, p. 657). A qualitative approach can also expand on the data obtained from traditional quantitative surveys, like those used to measure patient satisfaction. Qualitative inquiry strategies, such as those based on observation and participant narratives, allow us to explore a person’s lived experience and find the meanings that they place “on the events, processes, and structures of their lives and their perceptions, presuppositions and assumptions” (Al-Busaidi, 2008, p. 11). Atieno (2009) emphasizes the descriptive nature of qualitative research since the researcher is interested in “process, meaning and understanding gained through words or pictures” (p. 14).

As well, my ontology and epistemology influenced how I conducted my inquiry. Qualitative inquiry is compatible with my ontology, or my relativist view of reality. As a relativist, I believe that we know reality through socially constructed meanings. My epistemology, or way I come to know the world, I describe as social constructivist because I believe there are multiple ways of understanding and knowing the world that are constructed and dependent on the social contexts and time they occur. These multiple ways are reflected in the various approaches and learning styles adults use to acquire and process new information and how they communicate with others. Crotty (1998) suggests that we construct meanings as we engage with the world we are interpreting. A social constructivist approach assumes that we understand our experiences through the interactions we have with others, and within the social contexts these interactions take place. According to Creswell (2009), individuals construct

meanings of their experiences that are subjective, varied, and multiple, producing complex views for the researcher to explore. The literature review described adults as assimilators, accommodators, convergers, or divergers in the way that they learn. Their interactions, or the way that they communicate with doctors and other healthcare professionals may be passive, aggressive, or assertive. A social constructivist approach to research emphasizes exploring how the participants understand the situation being studied. The participant's nature, context, and processes of learning, as well as the perspectives of those who teach them, form the world they are interpreting.

A social constructivist perspective and qualitative methods requiring subjective, personal data were suitable approaches to answer my research question: How do illness narratives and arts-based artifacts deepen our understanding of the cognitive and emotional needs of a cohort of adult women with cancer?

Because we construct meaning as we interact with others, by asking open-ended questions the research participants could share their views about their experience with cancer and treatment. Information was gathered in the participants' own setting, since our social context influences how we make sense of the world. As we create meaning by interacting within our social context, understanding was generated inductively, concluded from data that was collected in the field.

I invited adult women with cancer to participate in individual interviews to access the complex meanings the experience of cancer generates. I allowed the meanings to emerge through the transcription, journaling, and writing processes to build a pattern of understanding about their experiences. During the individual interviews, I attempted to develop relationships of trust with the women that allowed me to explore their experiences in detail. I tried to absorb and interpret

these phenomena, so that I could describe them to others. Each participant and I were engaged and connected in the research encounter by the experience of telling, being listened to, and actively listening. I further interpreted and explained the reality we constructed during these interviews by creating textual and visual representations such as poems and drawings to invite the reader to engage in an aesthetic experience.

Arts-Based Methodology

When qualitative methods based in the arts are used in research, they create a unique opportunity for an emotional connection to be made among the participants, the researcher, and the audience related to the findings. Since quantitative patient satisfaction survey results may not be providing a full picture of what adults with cancer experience, qualitative arts-based forms of inquiry may deepen healthcare professional knowledge, facilitate changes in how professionals perceive their patients, and provide a catalyst to change the way cancer care is provided. Narrative inquiry is a way of gathering personal experience in the form of stories. Adding other arts-based methods, such as poetry and visual representations, allowed further exploration of this potential.

Narrative Inquiry

Narrative inquiry, a qualitative way to both gather and interpret data, is social constructivist in paradigm or worldview (Creswell, 2009; Guba & Lincoln, 2005; Pickard, 2012). Narrative research or inquiry involves studying the lives of individuals through their own stories. According to Clandinin and Connelly (2000), narrative, as both methodology and phenomenon studied, involves exploring how a person lives, tells, retells, and relives their experiences to understand how an individual's identity and social context shape experience. The researcher often re-tells or re-stories the participant's story "using structural devices such as plot, setting,

activities, climax, and denouement” (Creswell, 2009, p. 184). These commonly used structural devices are familiar to both non-fiction and fiction readers from many audiences. Clandinin and Connelly (2000) describe the final re-storied narrative as combining perspectives from both the participant’s and the researcher’s lives in a collaborative narrative. As such, my personal responses to the stories I hear will be important to record in my research journal.

Storytelling is not a solo event. Hurwitz et al. (2004) point out that, “In order to complete the story, a witness is needed” (p. 7). I became witness to the stories of six women in the interview process. The process of telling their stories gave the women a voice, respected their dignity, and encouraged their self-direction. The individual narratives that I wrote were based on each woman’s story, using her own words. They were a collaboration between us in the sense that, “In telling a story we not only use words in the way that others have used them before us, we add our meanings to theirs and thus build up a jointly authored narrative” (Hurwitz et al., 2004, p. 7). It is through the acts of telling a story and writing about that story that the “meaning emerges through interpretation” (Hurwitz et al., 2004, p. 5). I was aware that both the narrative inquirer and the participant are “always interpreting their pasts from their present vantage points” (Clandinin & Huber, 2010, p. 11). The processes of remembering and making meaning are selective and filtered through an emotional lens, as is the manner of interpretation. By inviting women with cancer to share their stories, their narratives became data for my inquiry. As Clandinin and Connelly (2000) suggest, I tried to preserve both the complexity and temporal context of their lived experience.

Photographs or objects we collect over our lifetimes often represent a memory of a special person or event. Clandinin and Huber (2010) describe how stories may also be triggered by personal artifacts such as photographs or “memory box” items (tangible representations of

memories) during interviews, as “creative field text gathering” (p. 215). Clandinin and Connelly (2000) refer to narrative inquiry memory triggers as “an archaeology of memory and meaning” (p. 114), perhaps because they serve as a way to dig more deeply into the richness of a person’s experience. The meanings that these artifacts hold are also open to interpretation and analysis in the narrative inquiry process. For this reason, I also invited participants to share objects, notes, and photographs that they felt had particular meaning for them in order to propel their stories beyond the limitation of words and prompt further aesthetic richness.

Arts-Informed Narrative Inquiry

Arts-informed research should encourage an emotive and thoughtful reaction in the audience. Arts-informed qualitative research methods (as described on p. 43) “infuse the languages, processes, and forms of literary, visual, and performing arts with the expansive possibilities of scholarly inquiry for purposes of advancing knowledge” (Cole & Knowles, 2008, p. 59). Arts-informed research is intended to engage the reader/audience in an emotional response. Additionally, Cole and Knowles (2008) speak to the ability of art forms to redefine how the complexities of a person’s experience are represented to a diverse audience, especially “communities and audiences including, but beyond the academy” (p. 61). In addition to adult educators and the education academy, I believe that textual and visual images will emotionally affect or resonate with doctors, other healthcare professionals, cancer educators, and adults with cancer and their family members, when elements of the narratives are published in scholarly journals or presented at professional conferences.

The medium of expression of research findings can include text forms, such as poetry (e.g., Guiney Yallop, 2014; Kendall & Murray, 2004; Leggo, 2008; Prendergast et al., 2009), performative approaches like theatre (e.g., Gray et al., 2003; Nisker, 2008), and image-based

methods such as painting, photography and sculpture (e.g., Israeli, 2011; Jay, 2011; Lidzey et al., 2008). Visual imagery, such as photographs or art objects used as a form of interpretation, can help to convey what are often very complex human experiences in terms of re-presentation of the narratives, to engage with and evoke empathy in the reader/audience. Art is not created for the purpose of making art but as a way to “involve the reader/audience in an active process of meaning making that is likely to have transformative potential” (Cole & Knowles, 2008, p. 62), to change attitude, perspective, or opinion by the experience of feeling.

I began my inquiry by gathering participants’ stories including details related to the arts-based personal artifacts that many of them shared with me. In addition to constructing individual written narratives of experience informed by the women’s stories and artifacts, I also constructed poems, drawings and a collective body map, since “knowledge or understanding is not always reducible to language” (Eisner, 2008, p. 5). This allowed me to express what I was feeling and to represent elements of the women’s stories. This aspect of Arts-Informed Inquiry, where qualitative research is influenced by an art form but not solely based in the arts can “enhance understanding of the human condition through alternative (to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible” (Cole & Knowles, 2008, p. 59). Multiple ways of expression could meet the various ways that adults acquire new information. Of particular interest to me is de Mello’s (2007) assertion that, in addition to being a way of creative field text gathering and research text presentation, Arts-Informed Narrative Inquiry may empower participants by inviting readers to draw their own conclusions as they create personal knowledge, while honouring the multiple perspectives of the participants. Participants’ words, voices, and perspectives are maintained and respected, yet enhanced by the form of creative expression used.

Lawrence, Nieves, Snowber, Kong, and Ntseane (2013) stress that embodied or somatic knowing, learning through our bodies, is the first way that we experience the world. Further, they acknowledge that, “For many of us, the body is source of discomfort or disease” (p. 390).

Pritchard (2016) points out that an ill person might even begin to see his or her own body as “the enemy” because of an ongoing or serious illness. One way we can become aware of what we know in our bodies, our embodied knowing, is through body-mapping. De Jager et al. (2016), describe body-mapping as a visual, arts-based, and reflective process that encourages embodied awareness. They state that it provides “access to information that would otherwise be overlooked or rendered invisible” (p. 4). By creating a visual representation of our experience, we can make what we have experienced in our bodies visible to ourselves and to others.

Creating a body-map involves “using drawing, painting or other art-based techniques to visually represent aspects of people’s lives, their bodies and the world they live in” (Gastaldo et al., 2012, p. 6). The images produced in body maps are symbols whose meanings depend on the experience of the person who created them. Following the process first used by Solomon (2008) and outlined in the AIDS and Society Research Unit (2007) workshop manual, I lay on the floor on a large sheet of canvas. A helper traced the contour of my body onto the canvas as I assumed two different positions, one superimposed over the other. The first pose was static and in profile. This outline would represent me in my role as the women’s helper. The second pose, overlaid on the first, faced the viewer and appeared to be in motion. This second outline would represent the women’s storied, embodied experiences. I asked each woman to view these life-sized body outlines (tracings) at our second meeting (see p. 144). I sent a colour photograph of the body outlines by mail to participants I was not able to meet with in person. Once I described the concept of embodiment, how body maps are made and can be used, and the purpose of this body outline (to represent their embodied experience), each woman suggested the structures and

features that she would like added to the outline to represent some aspect of her own experience (see p. 151). After I had met with everyone, I added pieces of fabric and other materials to the body outline to represent their body organs, the site of each woman's cancer, their physical and emotional scars, and the types of treatment that they had received. Once these features were added, the outline was transformed into a body map that represents their embodied experience. The resultant collective body map (see Figure 25) displays the site of each woman's cancer, the treatment(s) she received, and other personal features some women requested, superimposed onto a single outline.

De Jager et al. (2016) remind us that not all people find the process of producing a body-map helpful. Some may find it intrusive or uncomfortable if they are not ready to investigate their feelings in depth. I created a life-sized body map that was informed and directed by the participants and their narratives (also see p. 152) to visualize important aspects of their experience (to make the invisible, visible) and as a tool for disseminating the findings of the research. I used body mapping as a means of visually expressing the impact of the participants' physical, emotional, psychological, social, and spiritual experience of cancer to readers of this work. I also used it to express the impact that witnessing their stories had on myself. This provided a way for me to engage in an aesthetic experience as well. As I reflected on how I felt after I heard their experience stories by writing in my research journal, and as I wrote about their stories, I re-examined my values, beliefs, and perspectives as a healthcare professional, educator, researcher, and fellow human being. In addition to reinforcing the thematic analysis, it is my intention to use the highly visual collective body map as a means for communicating the women's experience of cancer and my own experience as researcher at conferences, workshops, and in publications.

Research Design

In the previous section I described the paradigm and methodologies that guide my qualitative inquiry. In this section, I will describe how I conducted the research, the methods I used to collect data, how I analyzed the data, and discuss considerations for ensuring research quality.

Ethics Application Clearance

My research proposal was reviewed by the Research Ethics Board of Brock University (see Appendix A) and clearance was granted May 5, 2016. All research involving human participants must receive ethics approval from the researcher's home university. I consider adults with cancer to be especially vulnerable because of the anxiety their illness causes and I took extra care to ensure their privacy and emotional well being.

Recruitment

To recruit participants for my study, I placed informational brochures (see Appendix B) in the offices of community cancer support organizations, such as the local cancer fund-raising foundation and the Canadian Cancer Society. Because of my previous work for the local regional cancer centre in an administrative capacity and the possibility that my actions could be perceived as coercive by others, I did not contact adults with cancer whom I had worked with in a professional capacity directly. However, women with cancer in the community who knew me, were interested in my research topic, and heard by brochure or word of mouth that I was recruiting, contacted me to ask whether they could participate. Some women learned about the study from women with cancer who had already agreed to participate. This form of recruitment is called the "snowball technique."

Selection Criteria

Participants were purposively selected in the sense that they were over 18 years of age, had a diagnosis of cancer, received some part of their treatment within the region of northeastern

Ontario, spoke and read English fluently, and completed active treatment (surgery, chemotherapy, and/or radiation) so that their stories could include a variety of transition points along the illness trajectory. Six English-speaking women with cancer were willing to tell me the story of their illness experiences. I did not set out to recruit only women. However, they were the first people who contacted me to express their interest and they met the criteria I had set.

Because the women had completed active treatment, I anticipated that they would feel less anxious or unwell at this point in their illness. As a healthcare professional, I know that activities such as reading study forms, listening to interview questions, concentrating, thinking, and speaking can be tiring when a person is unwell. I also expected that they would be more interested in participating in the research study with me once they were no longer juggling multiple medical appointments with their daily lives.

Initial Contact

Once I spoke with each interested woman by telephone to introduce myself, explain the purpose and expectations of the study and to ensure that she met the selection criteria (see Recruitment Script, Appendix C), I sent the research study information package (Letter of Invitation, Interview Guide, and two copies of the Informed Consent form) to her by mail (see Appendices D, E, and F).

Ethical Considerations

At our first meeting, I advised each woman that she could withdraw from the research study process at any time without fear of penalty. If this were to happen, I promised to delete, destroy, or shred all forms of her story, whether audio, visual, digital, or written. If a woman had become emotionally distressed (or physically unwell) while telling her story, I was prepared to suspend or terminate the interview. I gave each woman a list of resources for professional support in the community. I also contacted each woman by telephone 2 or 3 days later as a

follow-up to the interview to see if she had any questions or comments for me, and to ask whether she was distressed in any way by the interview experience.

First Meeting

To accommodate each woman's preference, we met in various locations, such as the woman's home, in a corporate boardroom or meeting room at the local public library, or by telephone for the initial interview and follow-up meetings. Women who knew and trusted me (and I knew and trusted them) invited me into their homes or a corporate boardroom. The private meeting room at the public library was used for the interviews with women I was meeting for the first time, since it was an accessible, safe, and power-neutral location. Although I had never been involved in their care in the past and would not be in the future, the women knew I had worked at the cancer centre. They did not have to invite me, a stranger and outsider, into their world physically. They also did not have to enter (or re-enter) my world physically. The public library was less likely to trigger any unpleasant memories that might be associated with the location of their care than a meeting room at the hospital, and I was less likely to be associated with the professionals who provided their care, in case this was a concern for any of the women who had not met me before.

The interviews lasted between 2 to 3 hours, depending on each woman's degree of wellness, and the length and complexity of her story. I used the Interview Guide questions (see Appendix E) only to stimulate telling of the experience story, since most women told their illness story freely, preferring a more conversational interaction. The Letter of Invitation (see Appendix D) included an invitation to bring personal artifacts with them to the interview if they had any they wished to share. Any discussions that occurred during the interview about personal artifacts, photographs, or body art were incorporated in the woman's interview transcript. Each interview

was audio recorded. Because the interviews occurred sequentially during a 4-month period (August–November of 2016), I continually refined my interview technique as I learned when to encourage the women to expand on their answers and how and when to redirect their focus to facilitate the telling of the illness experience stories.

Journal Notes

Since I take notes by hand when I listen to information presented orally to reinforce what I am hearing, I found it helpful to continue this practice during the interviews. In addition to following the sequence of each woman's story, I noted details about our location and described each woman's tone of voice, how fast she spoke, her choice of words, and my initial impressions of her emotional state. I also noted examples of how she preferred to learn (converger, assimilator, accommodator, or diverger) and her style of communication (passive, aggressive, or assertive). My observations highlighted points in her narrative where she experienced strong emotions, such as sorrow or anger and her associated body language, such as gestures. I also noted how each woman told her story. Did it begin in the present or the past? Did she jump back and forth between topics or between the past and present? What was the significance of this style compared to the basic elements of story structure and what was it telling me about the speaker? How could I relate to her style of storytelling?

Creating Transcripts

I transcribed the recordings after each interview for the experience of immersing myself in the stories since I am a visual learner. I found this to be a deeply reflexive but a time and emotionally intensive process. Based on this form of early analysis, I was confident I had reached recruitment saturation when themes and ideas emerging from the sixth woman's story echoed elements in other women's stories. I sent each woman a paper copy of her interview

transcript that included her explanation of her personal artifacts by mail to review and to make any corrections she felt necessary as a form of member checking. Using her corrections, I revised the interview transcript.

Second Meeting

I met with each woman a second time, either in person or by telephone, over a 1-week period (November 28–December 5, 2016). I mailed revised interview transcripts to the women I met by telephone and delivered these by hand to those I met in person. We discussed the next steps in the research process and the major storyline for the construction of each woman's individual narrative. The women viewed the life-sized body tracings I brought with me and made suggestions for construction of the collaborative body map, a visual representation of the women's collective experience that could be used to identify themes and for presenting the results of the research study.

Creating Individual Narratives

After our second meeting in December, I created an individual narrative for each woman told from a first-person perspective that focused on her illness story and her interactions with her doctors, and preserved her words, dialogue, and experiences. Each woman was assigned a pseudonym, selected at random. Names of other people in her story and locations were replaced with pseudonyms as well. The narratives were finalized by the end of February 2017 (see Appendix G).

Creating the Collective Body-Map

I also created a collective body map to illustrate the physical and the emotional impacts of their disease, treatment, and living with cancer. People with cancer often feel pressured to tell only positive stories of experience. The features of the body map were based on elements of the

experiences of all the women. After viewing the basic outline on the large canvas, each woman suggested the symbols of her experience she would like to see depicted on the collective body-map (see p. 151). The map was constructed between the second meeting (member-check) in December 2016 and the beginning of March 2017. The women later reviewed and provided final feedback on the finished body-map at the third meeting in April 2017.

Third Meeting

We either met in person or spoke by telephone one last time to discuss their impressions and comments about their individual narrative, the collective body map, and their research experience in April 2017. I incorporated their comments into their narratives, made changes and additions to the collective body map, and noted their comments about their research experience in my research journal. Each woman received a copy of her own revised transcript and individual narrative, and a photograph of the collective body map to keep.

Data Analysis

Transcription. As Tilley and Powick (2002) suggest, the process of analysis began during my transcription of the recorded interviews. I made decisions about the words I would keep and how to connect ideas while transcribing repetitive or disjointed passages. What conventions did I follow? I eliminated words that were used to connect thoughts or filled time to think, (such as *and*, *so*, *um*, and *ah*) and deleted the third occurrence of a repeated word, where I understood that the repetition was being used for emphasis. When participants used self-talk or repeated what someone else said, I used quotation marks (“”). At the end of a thought I used a period (.), and at the end of a complete idea or the end of a phrase/clause I used a comma (,). When the recording was unclear and I could not make out a word or phrase I used (indistinguishable).

Journaling. During and after each interview, while transcribing, constructing individual narratives and the collective body-map, and eliciting codes and themes, I journaled. My research journal, which I will share in the next chapter, is also part of my data. I documented thoughts, feelings, and connections that troubled me while I dreamed, performed mundane tasks and drove. I was immersed in these stories. Janesick (2016) states that “journal writing is a way of getting in touch with yourself in terms of reflection, catharsis, remembrance, creation, exploration and problem-solving, problem posing, and personal growth” (p. 135). Journaling helped to raise my consciousness and stirred the emotional pot as it simmered. She also recommends integrating poetry, drawings, sketches or photographs into the journal and reflecting on these to, “clarify your position and situate yourself in the research process” (p. 135). I created poems and drawings (my artifacts) to express what I was feeling (as a reflective activity), the connections I was making (as a deeper level of analysis), and to illustrate and support my analytic processes and conclusions for this dissertation. I could go beyond the limitations of words to express what I was feeling. These forms of analysis and expression also looped back to the narrative and thematic analyses that followed.

Narratives. The process of creating each individual narrative from the transcripts was both creation of data and a form of analysis. I wrote each narrative from the first-person perspective (using the pronoun “I”), using a *case synopsis* approach with the stories. Fischer and Wertz (as cited in Butler-Kisber, 2010) used a “case synopsis” method to make sense of, or interpret interview material. Butler-Kisber describes their process as re-reading and defining phrases or “units” of the transcript. Numbered lines in the transcript allow checking back so that the phrases can be ordered in the sequence the action occurred. This process allows the transcript to be condensed using the verbatim material as much as possible. Butler-Kisber states that this

process produces “a series of narrative synopses, and a final, ‘general condensation’” to illustrate the phenomena under study (p. 74). My process was similar. I re-read each woman’s numbered transcript closely several times looking for patterns and marking distinct phrases. I ordered the phrases sequentially, checking back with the transcript, and I rewrote each narrative three or four times to condense it, removing repetitive phrases and using each woman’s own words. With this process, I removed extraneous adjectives, adverbs and descriptions of other characters, places or events that perhaps spoke to her character or social context, but were not part of her illness story. I added my words only to link phrases and sequences in the story. I could hear the participant’s voice again in my head as I read and re-read, telling me what was important to her in her story.

Many illness stories contained additional compelling side-stories, especially where the woman’s story covered a longer period, introduced many characters, or several rounds of illness. The condensation process helped me identify plots, key characters, settings and themes of each side-story and I compared these with her dominant story to ensure the themes were consistent. I also listened for the themes, words and actions she repeated and emphasized with her tone, gesture, and emotion, linking these to the condensed narrative. On second or third readings, I also highlighted text that could become codes or themes in her illness experience.

Arts-informed ways: Poems and drawings. I explored how poetry can be used reflectively for analysis of the story and for representation. I found that I needed additional ways to express myself as I journaled to connect with my feelings and make sense of the needs and issues that the stories were raising. Writing notes was not making those connections for me. I drew pictures, scribbled disjointed thoughts, assembled and reassembled. Finally, I settled into a rhythm of connecting words that became short bits of prose and finally, poems. Leggo (2008) suggests that poetry allows us “ways to attach ourselves to strong emotion” (p. 168). This attachment appeared to be essential for me. Leggo also affirmed that “Poems tell stories, reflect

on lived experiences, express political manifestos, recount versions of history and tease the imagination to distraction” (p. 169). I learned that poems were an appropriate way for me to examine and understand these stories. Butler-Kisber (2010) describes both *found poetry*, where key words from the participant’s story are worked into poems, and *generated poetry*, “where the researcher uses her own words to share understandings of her own and/or others’ experiences” (p. 83). I used my own words to *generate* poems and haiku by focusing on an event or a participant’s reaction in a story, jotting down any pictures, metaphors, words and phrases that came to mind and reassembling these on paper to describe both the women’s experiences and my own as researcher. Prendergast et al. (2009) suggested that creating haiku would help me to condense my insights and emotions of their experience into clearer word images. Drawing allowed me to give my wordless thoughts a form or body. My drawings facilitated my writing, which facilitated my drawing. These intensive reflective processes often took several attempts over several days, taking me deeper into my insights.

Thematic analysis. I began the coding process while collecting and transcribing the stories and descriptions of the artifacts, which were my data. Saldaña (2009) refers to this, “circling, highlighting, bolding, underlining, or coloring rich or significant participant quotes or passages that strike you as...worthy of attention” as “pre-coding” (p. 16). I used different colour highlighters to identify similar ideas, quotes, and passages in the transcripts that stood out for me. I noted possible codes, topics, patterns, and themes in the margins of the transcripts. From these notes in the raw text, I created a column of preliminary codes which I categorized into final codes by creating a word or phrase. After much reflection, I conjoined these words and phrases into themes using phrases or sentences. As a novice coder and someone who needs to see the entire picture, I decided I would work with the data manually because I wanted to understand and be totally engaged in the process. Furthermore, Saldaña (2009) suggests that “There is

something about manipulating qualitative data on paper and writing codes in pencil that give you more control and ownership of the work” (p. 22). As Creswell (2009) described, I noted codes or ideas I recognized from the literature and my experience, as well as codes that I did not expect. The themes will be discussed in Chapter 5.

Methodological limitations. There are limitations to this qualitative research study, such as the influence of my bias as a researcher while designing the interview questions, facilitating the interviews, taking observation notes during the interviews, creating the written transcripts, and interpreting the participants’ stories. Additional limitations are the use of snowball sampling (additional recruitment by participants) and participant factors like social desirability bias (participant provides a socially-acceptable response).

Researcher bias. As the researcher and system insider, I came with prior knowledge of how the healthcare system works, my own personal experience with family and friends with cancer, and the cancer stories adults have shared with me because I have worked in a cancer centre. This prior knowledge allowed me to establish my trustworthiness and understand the context of the women’s experience. It also shaped my interpretations. I entered this research familiar with the strengths and weaknesses of the cancer system in terms of strategic plans and organizational and resource limitations. I am aware that who I am and what I know is what I write. Butler-Kisber (2010) suggests that to minimize researcher bias, “the researcher accounts for her researcher perspective and monitors this clearly and transparently throughout the work, and allows understandings to emerge” (p. 5). By making my research perspectives (see Interview Guide, Appendix E) clear from the outset of this work while conversing with participants, adhering to strict transcription practices that I gleaned from the literature, questioning my motives through reflective journaling, and member checking with my participants I believe that I reduced this bias.

Snowball sampling. Four of the women stepped forward to be interviewed because they had met me before in my previous role at the local cancer centre and heard that I was recruiting. In this sense, the first women who stepped forward were already aware of what my research interests were. Two additional women were recruited by one of these participants. Snowball sampling produces additional participants based on the trust they have in the person who recruits them. These additional participants likely shared characteristics similar to the woman who recruited them, such as language, interests, or experiences, since they were all members of the same women's peer support group. Atkinson and Flint (2001) advise that the use of snowball sampling reduces the possibility that the findings can be applied outside of the group of women who participated. Also, they point out that snowball sampling does not reach people who are not part of the social network and who might have a different story to tell than those who volunteered. Finding a larger number of participants can reduce the bias introduced because of the small, social group structure, however I stopped recruitment after six participants since saturation had been reached (these data were becoming repetitive) and I was not gaining new information. Qualitative research does not intend to generalize from the women's experience, only to deepen understanding of their emotional and cognitive needs.

Participant factors. The women who volunteered to participate in this research study knew from our first contact and the copy of the interview questions they received in the interview package (see Appendices D, E, and F) that I was interested in their experience of cancer and their information, communication, education, and emotional needs. They stepped forward because they had a story about their experience that they wanted heard. Did the women tell me what they thought I wanted to hear? Krumpal (2013) describes social desirability bias, when the participant gives the most socially acceptable answer to a question or tells the researcher what they think the

researcher wants to hear, as a possible limitation when using interviews to gather data. He advises using collection strategies that reduce anxiety during interviews to offset this bias. My interviews were more conversational in style, which I believe made the women comfortable while they shared their stories. I used the open-ended questions to prompt storytelling, allowing each woman to tell her story in her own way. I interrupted only to clarify what she said, to encourage her to expand her story and to redirect us when the interview went off track.

Evaluating Research Quality

I explored the multiple perspectives and experiences of my participants by choosing qualitative methods. Even with my good intentions, since my actions and interpretations are subjective, how do I know that my research processes and findings have quality? How did I ensure that I was trustworthy and honest, and my processes were fair and reflexive? Were the women's voices, the settings, dialogue, and actions in their individual narratives authentic? Would the intended audience recognize themselves in our constructed reality?

Guba and Lincoln (2005) propose trustworthiness and authenticity as criteria for evaluating qualitative research. I established my trustworthiness with the participants by (a) representing myself honestly and credibly based on my stated life and work experience; (b) being dependable, since I followed the steps that were set out in the Informed Consent form; (c) transferring elements of their real world social context to our collective body-map; and (d) ensuring that each person could recognize and confirm their original data. I believe that my work meets the authenticity criteria because I established an open, honest and ethical relationship with the participants from the first point of contact through to creation of their individual narratives so that, (a) their experience was fairly represented, (b) they gained insight into their own cancer experience, (c) they experienced some sense of catharsis or benefit by telling their story and

being actively heard, and (d) they had a sense of empowerment through the reflexive process of telling their narrative.

Like the concepts of trustworthiness and authenticity for qualitative research, Clandinin and Connelly (2000) discuss issues of voice, signature, and audience in narrative inquiry. They emphasize the relationship between the researcher's and the participants' voices during the writing of the research text and raise the danger of the researcher co-opting participants' voices. I understood that if I were not vigilant I risked using their voices for my own ends as a researcher. I did not want to silence their voices or change their stories since Kuipers (1989) describes how patient stories are routinely changed by medical professionals when patient histories are created for medical records. I believe that by being trustworthy in my processes and inviting member checking I mitigated this threat to validity. My dissertation committee continually challenged me to remain attentive to the rigor and validity of the research process.

Reflexivity. Guba and Lincoln (2005) and Clandinin and Connelly (2000) stress the importance of researcher reflection when conducting both qualitative research, and narrative inquiry. This includes self-reflection by the researcher and reflection on the processes of research. Reflexive research practice required me to continually assess my assumptions about the cancer system (see Chapter 1) and the dynamics of my relationship with my participants by looking in my rear-view mirror. I examined myself in my role as researcher by re-reading each transcript, identifying where my voice may have interfered with the participant's voice or when I failed to probe deeper, resolving to improve my actions. I journaled about the story elements that resonated or perturbed me in some way. I attempted to identify and challenge my assumptions about adults with cancer and my personal biases when my developing analysis agreed or disagreed with my professional and personal experience, the emotional and cognitive needs of

adults with cancer discussed in the literature, and my first impressions about the participants and their stories. I questioned my preconceived ideas about what their stories would reveal in my research journal. I reflected on my own experience as a healthcare professional and saw my actions through a more human and critical lens. I felt regret about missed cues to offer felt support, empathy and opportunities to genuinely connect with my patients. I also wrote poems and created drawings in my journal to express these feelings (see Chapter 5). These activities also helped me connect more deeply with the experiences of my participants and illuminated dominant themes in the transcripts that guided creation of their individual first-person narratives. I returned to their words in the transcripts, the individual first-person narratives, and the collective body map frequently while writing this dissertation.

I examined my research processes both during (reflection in action), and after (reflection on action), each interview. I evaluated how I asked my questions, how long I was speaking during each interview and whether I was interrupting the participant too frequently. When I did interrupt, was it for the benefit of the participant's story? Did my interruption help to keep the participant on track? By tracking these observations in my research journal, I adjusted the question prompts and my interview technique so that I could connect more deeply with each participant while the interview was still in process and for the next participant's interview. To ensure I remained faithful to each participant's story, I provided copies of the interview transcripts to each participant for review. I made the deletions and corrections each person requested, and provided them with a corrected version to keep. I also later provided the individual first-person narrative for review and discussion. By member checking the transcript and the first-person narrative and seeking their direction for construction of the collective body

map, I believe I constructed a trustworthy and authentic account that honoured each participant's experience and preserved their voices.

Pausing here to look at myself in my rear-view mirror, I realize that I have learned a great deal about myself and my ability to conduct qualitative research. I was greatly attracted to using arts-based inquiry because it had potential to create emotional impact and perspective transformation. However, while writing this dissertation I often struggled with my old habits of thinking and writing objectively. I began to wonder if I would ever write creatively and more honestly. Finding an emotional release in writing poetry, creating drawings and the collective body map was unexpected, exciting and liberating. I began to realize that I was experiencing the power of self-reflection to change perspectives. What I was writing and feeling propelled me into a free-fall of insight and receptivity to new ideas. I became more confident that I could use arts-based research to encourage perspective transformation in other adult learners.

CHAPTER FOUR: FINDINGS AND INITIAL ANALYSIS

In this chapter, I will describe the data that I collected to address my thesis question. These data include the narratives of six women that portray their cancer journey and their personal disorienting dilemmas. Several of the women either brought artifacts such as objects and photographs to enhance their stories, or shared body features that represent their own unique art. These visuals are also considered as significant data. I include my observations and reflections from my research journal in this overview, along with poems and drawings that were created from my perspective as observer and listener. Each woman's synopsis individual narrative is included in Appendix G. A collective body map, and my poems and drawings, will be considered in Chapter 5 in the data analysis discussion.

I documented these first-person stories to gain a deeper understanding of each woman's individual experiences of cancer to enhance the information available from quantitative patient satisfaction surveys. The individual stories also helped me to illuminate major themes that emerged from their illness experience story transcripts (see Categories and Themes in Chapter 5). Because the women had a copy of the Interview Questions before we met, they had time to preselect story elements that they felt comfortable to share with me and that were most important to themselves. Their transcribed stories contain very intimate details of their physical health, their emotional and mental states, their family life and their interactions with healthcare professionals and the medical system these are situated in. Through these stories I gained a deeper understanding of their cognitive and emotional needs, as well as the opportunity to discern their preferred learning and communication styles.

The women told me that they decided to participate because, either they knew and trusted me, or they knew and trusted the participant who recruited them. They also stated that they

wanted to tell me their stories to (a) have their stories heard by a person who understood how the cancer system functioned, (b) validate their experiences, and (c) help others with cancer by participating in my research project. Their reasons resonated with the words of Frank (1997) who said, “Telling stories of illness is the attempt, instigated by the body’s disease, to give voice to an experience that medicine cannot describe” (p. 18). Four of the six women also shared personal artifacts (poems, objects, photographs, or body art) and stories of the significance of these artifacts to their illness experiences with me. As anticipated, their arts-based personal artifacts added another, deeper dimension to their stories. I hoped that telling their stories would become a transformational and healing experience for them as well. By respecting their voices as authentic and meaningful, this process moved beyond the traditional, disempowering, transmissional medical model.

Overview of the Six Individual Narratives

The six women were white, English-speaking, heterosexual, and born in Canada. Each woman had received at least part of her cancer diagnosis or treatment in northeast Ontario. The women were diagnosed with different kinds of cancer and were between 17-53 years of age at the time of their first diagnosis. They had various levels of education and different work experience. Some had partners, children, and grandchildren. All participants expressed gratitude for the opportunity to tell their stories and the hope that the information could be used to positively influence the experiences of other people with cancer in future. Being able to tell their stories in their own way respected how adults learn and make meaning about their lives. As described in the literature review, storytelling is a self-directed, problem-solving, internally motivated, and empowering activity.

Taryn: A Silver Lining

Taryn was 31 years old at the time of her cancer diagnosis. She was a single parent to a

young son and worked as a healthcare professional in a large teaching hospital in a large city in southern Ontario when she was diagnosed with stage four (advanced) melanoma, which is a life-threatening skin cancer. Taryn did not have any prior experience with cancer in her family or in her work. After all her treatment options were exhausted, she relocated to a medium-sized city in northeastern Ontario to take care of her dying mother. Taryn now receives her follow-up care locally. She shared her story 10 years after her cancer was diagnosed. Taryn has experienced recurrences of her cancer, which have been managed by excisional biopsies. Because of the nature of her cancer, she cannot be declared “cancer free.” Taryn is no longer able to work due to the side effects of her treatment. She volunteers as a patient advisor for both the cancer and hospital systems.

“A practiced storyteller, Taryn delivered her story in a straightforward and compelling manner in her own living room at home. Her voice was animated and she appeared relaxed” (Journal notes, August 2, 2016). It was told chronologically and required little clarification or prompting. As a member of the healthcare team, Taryn expected and received full information about her health and participated actively in all decisions about her care initially. Her experience communicating with doctors and accessing care for recurrences in her smaller home city has not been as supportive or timely. She had to wait for referrals to specialists. “Like I knew what it was but I couldn’t get other people to believe me that I knew what it was.”² “It took a long time to get an oncology referral here.”³ Information has not flowed as easily either. Taryn is used to having access to all information about her health. She says that her current doctors do not provide her with enough information to manage her health. “There’s no communication.”⁴ She is optimistic that now that she has a family doctor and a medical oncologist locally, information and access to

² Taryn transcript, p. 28, lines 6-7

³ Taryn transcript, p. 27, lines 11-12

⁴ Taryn transcript, p. 27, line 15

timely care will improve over time as she develops relationships with her doctors that acknowledge that she is an expert about her disease and body and that she expects to be a partner in her own care. “A family physician having known me with other situations, just knowing my back history would have known to take it seriously.”⁵

Taryn’s story emphasizes her preference for an active role in her care and decision-making; she was assertive and responsive in her communication with doctors and other healthcare professionals, and active in her information seeking behaviours by searching out information and asking detailed questions. She preferred to receive her health information directly from her doctors and followed up with her own research on the Internet and through online patient forums. Taryn’s learning style is converging, as she is oriented to solving problems and attracted to technical tasks, doing and thinking. Taryn actively advocates for others in the regional cancer system.

For Taryn, a survivor of melanoma, the main emphasis of her experience is living with cancer despite a poor initial prognosis. She has endured very difficult treatment regimens and multiple recurrences, with her focus on surviving for her young son. “Her voice was most emphatic when describing her suffering and emotive when voicing her concerns for her son” (Journal notes, August 2, 2016). Taryn is resistant to the prevailing societal discourse that people with cancer must be strong or that a positive attitude will influence their outcomes, “Because then this will all turn out okay, but you’ve got to keep your chin held high, and you’ve got to keep fighting.”⁶ She has managed to find meaning through her experience, stating, “It offered me opportunity to realize that life is short, you put your best foot forward every day and not to wait

⁵ Taryn transcript, p. 29, lines 19-20

⁶ Taryn transcript, p. 34, lines 34-35

for tomorrow to spend time with people you love.”⁷ Although the fear of recurrence (the black cloud) is always present, cancer gave Taryn the opportunity to spend precious time with both her son and her dying mother. “She said that her black cloud had a ‘A Silver Lining’ (metaphor)” (Journal notes, November 29, 2016).

Taryn’s artifact. At one point in her story, Taryn showed me a scar on her arm to illustrate her experience with radiation treatment. Although she did not intend to bring any personal artifacts to the interview, we both agreed that her scar was indeed her artifact. For my interpretation of Taryn’s scar as an arts-based artifact, see Taryn: Researcher’s Reflection, Chapter 5 (p. 103).



Figure 11. Photograph of Taryn’s artifact. Area of scarring on right upper arm. A permanent side effect of radiation treatment.

Taryn: It actually looks like a little bit of art. I think that if you zoomed in on it enough that could be artful.

⁷ Taryn transcript, p. 26, lines 21-22

Researcher: It's your art. I had talked to you before about if you had any photographs from that time or artwork or anything; you have your own visual right there.⁸

Taryn: I actually look at it every day or so. I do find it interesting how the blood vessels, what do you call this?

Researcher: Telangectasia⁹.

Taryn: That's what it is. And the scarring that's there as well, I find it very abstract art looking.¹⁰

Eva: Because It Breaks Your Heart

Eva is a survivor of four different cancers. She has lived in a medium-sized city in northeastern Ontario all her life and has received all her treatment locally. She was married with a young son and daughter when her first cancer, uterine cancer was diagnosed when she was 39 years old. Eva had breast cancer at age 51, colon cancer at age 62, and another colon cancer 2 years ago at age 64. She sees her oncologist on a regular basis because of the likelihood of a recurrence or spread of one of her cancers or the development of a new cancer. Her experience of cancer with members of her own family has not been positive. Many of Eva's close relatives have died from their cancers. She is retired from the field of business and is a grandmother. Eva volunteers as a patient advisor for the regional cancer system and leads a peer support group for women with cancer.

Eva has spoken about finding her cancer at public events, about living with cancer to peers in support groups and what it is like to be a cancer patient to cancer centre staff as a member of committees and working groups. When Eva first read the Interview Guide questions,

⁸ Taryn transcript, p. 14, lines 6-7

⁹ Broken blood vessels

¹⁰ Taryn transcript, p. 14, lines 12-15

she said that she knew what she wanted to tell me about by comparing two specific aspects of her cancer experience. “She was animated and comfortable sharing her story with me at the dining room table in her home” (Journal notes, August 30, 2016). Because of her cancer history and her genetic profile, she knows (and greatly fears) that she may face new diagnoses (or recurrences) in future. “Because even when you’re well, there’s not a day or a minute that goes by that there isn’t a cloud (fear of cancer).”¹¹ Her ability to cope is strongly related to the connection she has made with her doctors. Eva places major emphasis on her relationship with her doctors. She expects to be an active participant in her care, she values direct communication and dialogue and is active in her information seeking behaviour by asking questions. When the doctor provides full explanations, answers her questions, deals with Eva’s concerns and medical needs quickly, she feels that her emotional needs are also being met. “The doctor has to look at you. He’s got to see all of you. He can’t just see the cancer. If he just sees the cancer, he won’t be able to tell you anything, he won’t be able to look you in the eye.”¹²

Eva is diverging in her learning style since she likes to gather information, is interested in people, and facilitates a peer support group. She is always concerned for the impact her cancer diagnoses will have on her family and about having to put them through the emotional distress of yet another cancer. “They want to believe that you’re well. And you’re going to tell them you’re not well?”¹³ Eva gained knowledge, emotional support, and confidence by joining a women’s breast cancer peer support group and a breast cancer dragon boat team. She later formed and still facilitates another women’s peer support group that empowers women with all kinds of cancer. “Eva describes her cancer experience as stressful, ‘Because it Breaks Your Heart’ (metaphor)” (Journal notes, November 29, 2016).

¹¹ Eva transcript, p. 27, line 14-15

¹² Eva transcript, p. 12, lines 10-11

¹³ Eva transcript, p. 27, line 19

Eva's artifacts. When I arrived at her home for the interview, Eva had carefully arranged several items that were important to her in a tableau on her dining room table. I was fascinated by her artifacts and grateful that she shared them with me. She explained how each object represented an important part of her life with cancer. Her fear of running out of time was very clear to me and this realization impacted on me emotionally. For my interpretation of Eva's personal artifacts, see *Eva: Researcher's Reflection*, Chapter 5, (p. 104).

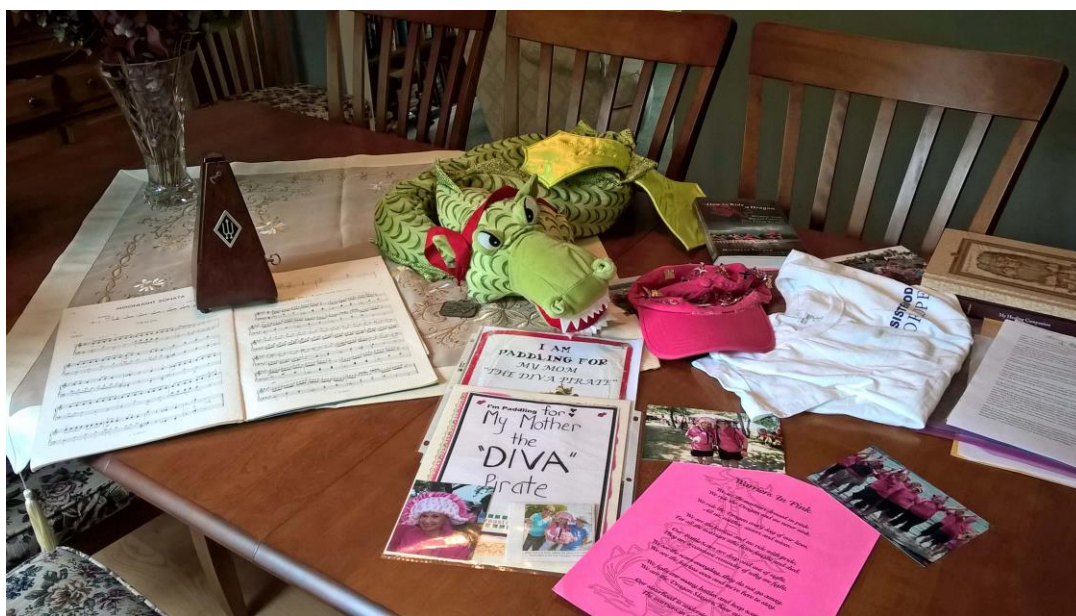


Figure 12. Photograph of Eva's artifacts. From upper left to lower right, clockwise: sheet music and metronome; toy dragon mascot; hot pink hat with angel pins; book about dragon boating; *Women with Cancer*¹⁴ T-shirt; Eva's journals, notebooks and other self-help books; dragon boating photographs; and Eva's poem *Warriors in Pink*.

The sheet music speaks to the importance of music in reclaiming her "voice," which is a metaphor for how Eva regained her ability to play the piano after developing peripheral neuropathy in her fingers.

¹⁴ Pseudonym.

When I was waiting for results the best thing I could do was play music because you have to concentrate on the treble clef and the bass clef and in my mind there wasn't room to think of anything else!¹⁵ But when I had chemo I couldn't play my real piano anymore because my hands and my fingers were not good anymore.¹⁶

Eva resisted getting an electric piano because, "those aren't real pianos."¹⁷

So, one day when I was waiting for some very, very, disturbing news with tests I opened up that box and I played it (the electric piano) until four o'clock in the morning. And it's my best friend now. So, you have to try new things. You always have to venture forward and not look so much at what you've lost but what you can gain.¹⁸

The metronome signifies "time" and her fear of running out of time with her family. Eva said, "And my metronome is time, so that's part of it."¹⁹ The toy dragon embodies her enemy, cancer.

I had to personify cancer into something tangible, something I could fight.²⁰ Well, like I told you in my poem, when I became a dragon slayer, I went out shopping one day and there he was. And I bought him and I took him home. I said to him, "You're coming on every dragon boat with me and you're going to see the fierceness of the group that I've got. And we're going to fight you; we'll keep you down."²¹

The pink hat represents both the support she received from the people around her and their expectations that Eva would continue to fight her cancer.

I bring the hat because when I was ill everyone was throwing little angels at me and I thought, where will I put them all, you know? So, this pink hat, when we did practices I

¹⁵ Eva transcript, p. 2, lines 1-3

¹⁶ Eva transcript, p. 2, lines 4-5

¹⁷ Eva transcript, p. 2, lines 8-9

¹⁸ Eva transcript, p. 2, lines 11-14

¹⁹ Eva transcript, p. 2, line 15

²⁰ Eva transcript, p. 1, lines 11-12

²¹ Eva transcript, p. 2, lines 28-31

would put this on and hope there would be no lightening because if I ever got struck I would be a very sad person. But it just goes to show you how many people were on my side, were fighting for me.²²

The *Women with Cancer* T-shirt symbolizes how she became an advocate for herself and other women with cancer by forming her own women's peer support group.

Because that path is long and hard and if you're by yourself, and a lot of our women are because husbands leave, unfortunately. Not all of them but some of them do leave. And they're left with children, they're left with not that support. You know, because at our age our parents are too old to help us, so there's a lot.²³ It's a good support group.²⁴ But it certainly is good talking to somebody who has already been there.²⁵

Eva said that the journals and self-help books helped her learn how to cope with cancer.

When I first wrote about it (cancer) in this journal I tried to make fun of it, of course, because that's my way of dealing with a lot of things.²⁶ This book was very precious to me because I wrote many, many funny stories about things that were really not so funny. I just turn them into funny stories.²⁷

The dragon boating artifacts (photographs, book) emphasize the dragon slaying and women warrior themes and the ability to fight cancer. They are tangible reminders of the time Eva spent with her daughter while dragon-boating which are precious to her.

So, my daughter and I joined together. She hadn't spoken about cancer for at least two years after my cancer because she was young; she was 17. Then one day she saw the

²² Eva transcript, p. 3, lines 3-6

²³ Eva transcript, p. 17, lines 7-10

²⁴ Eva transcript, p. 17, line 29

²⁵ Eva transcript, p. 17, line 35

²⁶ Eva transcript, p. 5, lines 19-21

²⁷ Eva transcript, p. 5, lines 25-27

dragon boats and she said, “C’mon mum,” And I thought, like I’m old and she’s young, anyways I said okay. So, when I got on there they wanted me to be the drummer so she got on the back and I got on the front, and the chair is this big – it’s very small and it’s very high up and I got up and I thought, I can’t do this because I’m going to fall. And I looked down at the end of the boat and there was my daughter smiling at me and talking with all the girls who had lost their mothers, and I thought, I have to fight that dragon again and I have to sit here on this boat and I have to dragon boat and I did, and I love it. And I love it to this day.²⁸

Her poem, *Warriors in Pink*, speaks to the power of fighting the dragon (cancer) together as a group of women warriors with breast cancer.

Warriors in Pink

We are the warriors dressed in pink.
 We ride the Dragon and we never sink.
 We ride the Dragon every day of our lives,
 All us mothers, sisters and wives.
 We are the fearless and we ride with pride,
 For all the warriors who have fought and died.
 Our battle scars are deep and out of sight.
 They are a constant reminder of why we fight.
 We see the scars every day, they do not go away.
 We are the fearless ones and we’re here to stay.
 We fight our many battles and keep score.
 We are the Dragon Slayers, hear our roar.

²⁸ Eva transcript, p. 2, line 31; p. 3, line 2

Our sisterhood is understood and clear.

The warriors in pink are here!

Eva, (2001), poem used with permission.

Pink is the colour that represents breast cancer fundraising. Some of the women's scars may not be visible, like their emotional scars and their fear of recurrence, but the fight against cancer carries on every day of these women's lives. Eva summarized her poem by saying, "I have seen that dragon skulking around but he knows better than to mess with me and my army of dragon slayers defending me and all who are fighting this disease."²⁹

Erin: There Is Life After Cancer

Erin was diagnosed with an early stage cervical cancer, three years ago, when she was 50 years old. She has lived in a medium-sized city in northeastern Ontario all her life and has received all her treatment locally. She had two daughters and a son from a previous marriage and grandchildren at the time she was diagnosed and treated. Erin also had a partner and supportive friends she could count on during her illness. She did not have any prior experience of cancer within her family. Erin worked as a cleaner in a healthcare facility and she returned to work after her treatment was finished. Erin is a member of a peer support group for women with cancer.

"Erin and I met at the public library meeting room. Although we were meeting for the first time, I sensed that Erin made up her mind about whether she could trust me with her story quickly. Her story was told with anger. The anger was in her voice and in her tense body posture. Her gestures were short and emphatic. Her eyes held mine intently" (Journal notes, September 19, 2016). Erin's story highlighted how she found her voice through gaining information and the experience of cancer and treatment. She related that her concerns about her health were ignored by her family doctor from the outset. When she finally heard her diagnosis, Erin shut down

²⁹ Eva transcript, p. 1, lines 23-25

emotionally. “The world basically shrunk down to tunnel vision.”³⁰ She was not expecting to hear that she had cancer. “I’m not thinking anything of it because nobody ever mentioned cancer to me, ever.”³¹ Her information seeking style is passive and she is not comfortable asking for information directly. “You just go where they point and if you do have any questions, you don’t know who to direct it to.”³² Erin is accommodating in her learning style as she relies on others for information, prefers to work in teams and often reacts on intuition rather than facts. Of her cancer experience, Erin says, “Put the humanity back in it, because we all have feelings.”³³ She suffered physical, emotional and economic hardship. She needed money for food because she was not able to work. “There was no offer of any assistance whatsoever to help me pay for anything. I had to pay for everything myself.”³⁴ Erin’s crises were not addressed, her specific needs were not assessed or recognized. She did not have information about the system supports that were available but not offered to her. Getting information and emotional support from the supportive care department would have given Erin hope and helped with coping. “I didn’t access supportive care until almost the end of everything where I could have used it a little more at the beginning to help me process everything.”³⁵

Erin found that standard educational supports like the information binder and the group learning sessions were not helpful to her. “It’s very impersonal and meanwhile cancer is a very personal thing.”³⁶ She gained confidence and her voice through her cancer experience and by joining a woman’s peer support group. “As she spoke about the group Erin appeared to relax physically. Her facial expression and body language softened. Her voice and gestures were less

³⁰ Erin transcript, p. 2, lines 5-6

³¹ Erin transcript, p. 1, lines 32-33

³² Erin transcript, p. 18, lines 4-5

³³ Erin transcript, p. 30, lines 6-7

³⁴ Erin transcript, p. 17, lines 43-44

³⁵ Erin transcript, p. 17, line 48; p. 18, line 1

³⁶ Erin transcript, p. 6, line 42

emphatic” (Journal notes, September 19, 2016). The group provided Erin with information and emotional support. “I get support from my support group, *Women with Cancer*. If I have any questions or whatever, there’s always someone in the room that either knows of a place or has been through it and says, ‘Call so and so.’”³⁷ She has reached out to other people with cancer to provide advice and hope. “You will get through it and you’ll be okay. Yeah, there’s life after this.”; “I was elated that I was able to give her hope.”³⁸ Fortunately, Erin’s ongoing relationship with her radiation oncologist is supportive. “I’ve got high praises for her, she’s a wonderful doctor.”³⁹ She is playing a more active role in her healthcare by asking questions. “Erin’s new mantra is, ‘There is life after cancer’ (metaphor)” (Journal notes, November 28, 2016).

Loraine: She Is My Saviour

Loraine was diagnosed with stage two (early stage) thyroid cancer about a year ago, at the age of 35. She has lived in a medium-sized city in northeastern Ontario all her life and has received all her treatment locally. Loraine is single, does not have any children and worked as a food handler in an educational institution. She did not have any experience with cancer within her family and friends. Loraine has a learning disability and an anxiety disorder. She has returned to work. Loraine is a member of a peer support group for women with cancer.

Loraine tells an overwhelming story of vulnerability. Her story was narrated as a jumble of elements, often in contradiction to each other. It was difficult to hear her “voice,” to learn what she thought or felt during the interview. “Loraine spoke in short sentences, referring often to her copy of the Interview Guide. I wondered if she was feeling uneasy with me since she was meeting me for the first time” (Journal notes, September 24, 2016). At the beginning of the interview she presented her experience of her cancer diagnosis and treatment as only positive,

³⁷ Erin transcript, p. 24, line 47; p. 25, line 1

³⁸ Erin transcript, p. 29, lines 35-36; 38; 39-40

³⁹ Erin transcript, p. 5, line 11

but with persistent, gentle probing more details such as her emotional and learning needs emerged. She manages to cope with life and her illnesses because of the support that she gets from her mother and other friends around her. “So, my mother came with me and she explained it to me. Because when I have someone with me I can better understand.”⁴⁰

Loraine is extremely passive in her information seeking behaviours. “When I’m by myself, my anxiety level hits the fan.”⁴¹ If her mother or another friend is not with her she has difficulty understanding and does not admit when she does not understand the information she is given. “My mother would have a lot more questions.”⁴² Loraine’s healthcare professionals tend to assume that her mother (or someone) will take care of all her information needs. She said that her doctors have never asked her if she understands what they are telling her. “Oh, they never ask me that.”⁴³ Loraine’s learning style is accommodating since she gravitates towards being a group member and depends on others for her information and interpretations. Loraine admires powerful women and would like to be a strong woman herself. She also sees herself as a crusader for other women, which she has enacted by joining a women’s cancer peer support group and other advocacy groups for women. “I’ve been through it so I want to help other women.”⁴⁴ “Although Loraine refers to Sainte-Jeanne-d’Arc or Joan of Arc as being her protector, ‘She is my Saviour’ (metaphor), I wonder if she may also be referring to her own mother” (Journal notes, November 30, 2016).

Loraine’s artifacts. “Loraine carefully laid out her artifacts as soon as she sat down. She seemed very nervous so I asked her to tell me what she had brought with her today. Loraine visibly relaxed and gradually leaned forward to touch each one as she spoke” (Journal notes,

⁴⁰ Loraine transcript, p. 3, lines 23-25

⁴¹ Loraine transcript, p. 17, line 28

⁴² Loraine transcript, p. 16, line 17

⁴³ Loraine transcript, p. 16, line 8

⁴⁴ Loraine transcript, p. 18, line 5

September 24, 2016). For my interpretation of Loraine's personal artifacts, see Loraine: Researcher's Reflection, Chapter 5 (p. 107).



Figure 13. Photograph of Loraine's artifacts. From left to right, the figurines are: Angel of Miracles; Angel of Healing; Sainte-Jeanne-d'Arc or Joan of Arc; and the Virgin Mary. A button necklace lies in the foreground.

She explained that she received the angels as gifts from a family member and a friend during her illness.

Researcher: Tell me about this angel. [pointing to the left]⁴⁵

Loraine: Well, I'm into a lot of angels and that one—I was in the hospital and my aunt gave me that as a present while I was in the hospital.⁴⁶ That one [touching the figure in the middle] was a present from the president of the College.⁴⁷ He was always very understanding. It was like if you ever needed to talk to someone, he was always there.⁴⁸

⁴⁵ Loraine transcript, p. 19, line 16

⁴⁶ Loraine transcript, p. 19, lines 3-4

⁴⁷ Loraine transcript, p. 19, line 17

⁴⁸ Loraine transcript, p. 19, lines 20-21

Loraine found the Virgin Mary and Sainte-Jeanne-d’Arc or Joan of Arc figurines at church bazaars.

Researcher: I’m going to go to this one, so this is a figure of—is that Mary? [pointing to the right]⁴⁹

Loraine: I came across a Virgin Mary and I thought she was beautiful.⁵⁰

Researcher: I’ve left the saint for last. [pointing to the middle]⁵¹

Loraine: Oh, yes, she is my saviour.⁵² Oh, she’s very special to me. She’s just so beautiful. Even people give me compliments about my hair and they tell me, you look like Joan of Arc.⁵³ Every time when I feel sad I look at her. [laughs]⁵⁴

Loraine described her button necklace as symbolizing her “circle of friends” around her.

Researcher: Last but not least, I’d like you to tell me about your button necklace.⁵⁵

Loraine: These give me strength. It’s like a circle; it’s like a circle of friends.⁵⁶ And it’s just really, really good 'cause it guides you into the light and it says wow, you’ve got very good friends and they’re there for you.⁵⁷

Holly: There Is Always Hope for a Cure

Holly was 17 years old at the time of her diagnosis with an early stage soft tissue sarcoma. She lived with her father in a rural area in central-western Ontario, attended the local high school, and had a part-time job as a sales clerk. Holly had a boyfriend at that time. She did

⁴⁹ Loraine transcript, p. 19, lines 33-34

⁵⁰ Loraine transcript, p. 20, lines 6-7

⁵¹ Loraine transcript, p. 20, line 10

⁵² Loraine transcript, p. 20, line 11

⁵³ Loraine transcript, p. 20, lines 19-21

⁵⁴ Loraine transcript, p. 20, lines 28-29

⁵⁵ Loraine transcript, p. 20, line 32

⁵⁶ Loraine transcript, p. 21, lines 3-4

⁵⁷ Loraine transcript, p. 21, lines 6-7

not have any prior experience of cancer within her family. Because of her age and type of cancer, Holly was referred to a large teaching hospital in southern Ontario for her treatment. Her treatment has left her with a physical disability and she received cancer-related physiotherapy in a medium-sized city in northeastern Ontario while she was in university. Since it has been 5 years since her diagnosis, Holly was recently declared “cancer free.” She became a healthcare professional after she graduated from high school and is working in her home community.

Holly’s interview was conducted by telephone. “She was relaxed, confident and her voice was quite animated as she related her experience story” (Journal notes, October 12, 2016). Holly’s story also emphasizes her vulnerability and need for support, but for reasons that were different than Lorraine’s. Holly was vulnerable because of her youth and inexperience with life and illness. “I felt like I was an adult at that time, but now being older, I realize that I was very much a child. And I had different needs than the rest of the patients.”⁵⁸ Holly was passive in her communication, information seeking behaviours and participation in her care. “I didn’t feel as if my opinion mattered, ‘cause it was just being over-spoken anyways.”⁵⁹ She had difficulty being taken seriously by doctors, her diagnosis was significantly delayed and her first surgery was not performed properly. “People treated me like I was a kid and didn’t know anything. They didn’t take me seriously.”⁶⁰ She often attended important medical appointments by herself and made decisions without knowing what questions to ask. Holly’s healthcare professionals made assumptions about her ability to cope and she was not offered disease specific information, age appropriate resources or emotional support. “As far as any classes or support groups or stuff like that, I wasn’t offered anything.”⁶¹ She needed emotional support from her family, specifically

⁵⁸ Holly transcript, p. 23, lines 25-28

⁵⁹ Holly transcript, p. 8, lines 39-40

⁶⁰ Holly transcript, p. 5, lines 37-38

⁶¹ Holly transcript, p. 15, line 4

her father, but did not get enough of the support she needed throughout her illness. “And I was very anxious, looking back at it now.”⁶² After hearing the diagnosis and not knowing where else to go for information and support, Holly approached a trusted teacher at school. “I remember for the first time, breaking down and telling him what the doctor said.”⁶³ Holly found support from friends and other healthcare professionals she met along the way: the concerned chiropractor who encouraged her to insist on medical investigation, the radiation therapist who befriended her during her radiation treatments, and a community physiotherapist who helped with her rehabilitation after her extensive surgery. She did not manage to build a relationship with her radiation oncologist as she rarely saw him during the course of her treatment: “I really didn’t have a rapport built with him of any nature, and I could honestly not even tell you what he looked like.”⁶⁴

Holly was not adequately informed about the late effects of her radiation treatment. “As far as permanent issues, I was specifically told not to expect anything.”⁶⁵ She has since learned that she is at risk of developing another cancer because of her radiation treatment. Holly has found her voice after completing training as a radiation therapist. She is very well educated about her cancer and treatments and is very active in information seeking and communication. “After being through school, I did end up actually going [to the hospital] and getting all of my records—like, my surgical records—and reading through them. So, I had a better understanding of my case.”⁶⁶ Holly is assimilating in how she learns. She requires clear, logical explanations and prefers having time to think things through. Holly now speaks to healthcare professional audiences about her experience to promote age-appropriate services for adolescents and young

⁶² Holly transcript, p. 11, line 2

⁶³ Holly transcript, p. 5, lines 9-10

⁶⁴ Holly transcript, p. 10, lines 17-18

⁶⁵ Holly transcript, p. 13, lines 30-31

⁶⁶ Holly transcript, p.23, lines 25-28

adults with cancer. “After hearing that she was declared cancer-free after 5 years, Holly said, ‘There’s Always Hope for a Cure’ (metaphor)” (Journal notes, December 5, 2016).

Holly’s artifact. At the end of her story, Holly and I discussed the tattoo that she had done to celebrate being declared “cancer -free” 5 years after diagnosis and treatment. I had seen the tattoo in an earlier stage of development and she sent me a digital photograph of the most recent changes before the interview. Although she did not think that she had any personal artifacts to offer for the interview, once she told me about what it meant to her, we both agreed that her tattoo was a very important artifact. For my interpretation of Holly’s tattoo as an arts-based artifact, see Holly: Researcher’s Reflection, Chapter 5 (p. 110).



Figure 14. Photograph of Holly’s artifact. The tattoo wraps around Holly’s left forearm, beginning above her wrist and extending just above her elbow. The photographs are taken from various angles around her arm to present all the details of this beautiful work of art.

Researcher: Did you do anything to celebrate at that time?⁶⁷

Holly: I ended up celebrating, I guess, in a way, when I got back home and got my tattoo to be my symbolic piece of what I went through.⁶⁸

Researcher: For the purposes of the recording, would you describe your tattoo, please?⁶⁹

Holly: Of course. My tattoo is on my left arm—my left forearm—as you’re standing anatomically correct, it’ll be on the anterior portion—so the palmar [next to the palm] portion of my left arm. And it starts at my wrist and goes up just over my elbow and kind of actually almost wraps all the way around my forearm, I should say, and it starts at the bottom with a little swirl and goes up into one, two, three—three different stems. So, the first two stems go into two different carnation flowers, and the carnation is the flower of January, and that was the month I was diagnosed in. And above them is a rather large piece in the tattoo—the rose. And it runs from the middle of my forearm up through my elbow. And the rose is the flower of June, and that was the month I had my final surgery and they started counting my remission from. And then I mentioned back at the very beginning, there was three stems.

The third stem starts at the bottom and then branches off to either side of the tattoo and goes up. It’s actually more of a vine than a stem, ‘cause of the type of flower it is. It’s a sweet pea. So, it’s a vine and it goes all the way around either side of the tattoo and up to the top with all

⁶⁷ Holly transcript, p. 21, line 13

⁶⁸ Holly transcript, p. 21, lines 18-19

⁶⁹ Holly transcript, p. 21, lines 22-23

the sweet pea flowers, and they are one of the flowers of April, which was the month of my last appointment when I got the all clear. And the reason the three stems start together is I have the starting of my diagnosis, and there's always a hope for a cure. And that's why the sweet pea, which is the last flower, also starts in the very beginning.

And the reason it's on my left arm was because when I woke up from my final surgery, I didn't temporarily have the use of the left hand, and I had to rebuild the strength and retrain myself. And it also covers up all the pinholes from various IVs and stuff while I was in the hospital.⁷⁰

Erica: Two Little Black Clouds

Erica was 53 years old when she was diagnosed with an aggressive ovarian cancer two years ago. She is at high risk for a recurrence of her cancer and for developing a second cancer. Erica lived in a small city in northeast Ontario when she was diagnosed, and received the rest of her treatment in a medium-sized city in northeast Ontario. Erica received emotional and practical support from her partner, family, and friends. She does not have any children. She recently retired from her highly respected position in business to concentrate on managing her ongoing health challenges. A recent test has shown a new area for concern that requires investigation. Erica will be referred to a large teaching hospital in southern Ontario for further treatment. She volunteers on a hospital board and as a patient advisor for the cancer system at both the regional and provincial levels.

"We met in the empty board room at Erica's place of employment. She immediately sat at the head of the table, a place she would be very accustomed to as the organization's leader. Erica told her story easily and chronologically with little prompting. She recalled details about

⁷⁰ Holly transcript, p. 21, line 24; p. 22, line 5

her disease and treatment precisely from memory” (Journal notes, October 12, 2016). A very pragmatic person, Erica approached her cancer as a problem to be addressed as quickly as possible. She managed her original diagnosis of an aggressive ovarian cancer and treatment in a straight forward manner with the support of her family members and close friends. Erica tended to understate her emotional reactions during her narration. “It was a surprise when I heard the diagnosis because I’d never heard a cancer diagnosis before, but I don’t recall feeling immense emotion about it.”⁷¹ “Her narrative emphasizes her fear of either a recurrence of her original cancer or developing a new cancer, ‘Two Little Black Clouds’ (metaphor)” (Journal notes, October 12, 2016). She did express more emotion when she described the exchange with her oncologist who was concerned about a lump in her breast, “That was probably the one thing that freaked me out the most is that I’d have ovarian cancer and breast cancer at the same time.”⁷² While Erica does not have breast cancer, unfortunately her fear of another cancer has been realized. Three years after diagnosis and treatment she is now facing either a recurrence or a second cancer diagnosis. “Every time I go in for my appointment to Small City, I’m anxious now that I know I have something else going on.”⁷³

Erica is direct in her communication, and expects complete information and timely action. “Waiting is frustrating when you know you have something in you and you know that you had something very deadly in you before. So that’s the frustrating part is I just want it out.”⁷⁴ Erica is an active participant in her care, values direct and complete information. “I advocate for myself and which I think as patients in the healthcare system we need to take care of ourselves

⁷¹ Erica transcript, p. 2, lines 26-28

⁷² Erica transcript, p. 3, lines 45-46

⁷³ Erica transcript, p. 17, lines 43-44

⁷⁴ Erica transcript, p. 10, lines 40-42

too.”⁷⁵ Erica has a converging learning style. She is comfortable with technology, uses new information to solve problems and takes action. A professional business woman for many years, she recently retired and will be directing her energy to managing her own care. Erica actively seeks out her own information on the Internet from medical websites and other women with ovarian cancer and communicates directly with her doctors. Erica did not look to her doctors for emotional support but acknowledged that when she recently heard about a new suspicious mass from her oncologist she felt shock and some distress.

There was a moment when I left Dr. C’s office where I had now been told I had something else and I walked out into the hall and there’s nobody there. I broke down because it’s like, “Oh my God, now what?” But there was no offer of any other kind of support.⁷⁶

The doctor and the nurse did not anticipate that the news would be upsetting to Erica, and they did not ask how she felt or offer professional support. “I don’t recall either him or the nurse asking how I was doing, was I okay, did I need a few moments?”⁷⁷ Erica needed and would have appreciated emotional support at that time.

The stories that these six women shared and the dominant themes they expressed tell us a great deal about their emotional and cognitive needs. Similar to Abel and Subramanian (2008), who gathered the stories of women living with breast cancer, without an opportunity to tell their stories, much of this information might not have been accessible. Yet, their stories can provide doctors and other healthcare professionals with so much more information about all their needs as a person with cancer, such as their fears, uncertainties, confusion and their need for hope.

⁷⁵ Erica transcript, p. 10, lines 29-31

⁷⁶ Erica transcript, p. 11, lines 17-21

⁷⁷ Erica transcript, p. 12, lines 23-24

Each woman said how good it was to tell their stories and to have their experiences validated.⁷⁸ I will examine and discuss the themes that emerged from each woman's narrative in Chapter 5. My research journal, where I recorded my observations and interpretations in various forms, is also primary data to be analyzed.

Overview of Researcher's Journal

Personal journals serve as a place where researchers can "interrogate their assumptions, note reflections and experiment with interpretations" (Butler-Kisber, 2010, p. 69). By noting my thoughts, feelings, doubts and concerns throughout the research process, I was making observations about my inner experiences, and recording myself as the "researcher experiencing the experience" (Clandinin & Connelly, 2000, p. 87). I was creating data. I began journaling during the interviews to note my observations, impressions and the early connections I was drawing. The journaling process continued while I created the transcripts and the illness narratives and throughout the analysis. My journal insights and reflections also guided construction of the collective body map. Sufi scholar Jalaluddin Rumi, whose writings date from the 13th century, highlighted how truth could be conveyed in more than one way by saying, "A tale, fictitious or otherwise, illuminates truth" (Seeker After Truth, 2006, para. 15). Rumi's words encourage using multiple modes of expression.

Bearing Witness

To bear witness is no easy task. It can weigh heavy on the heart and mind at times. However, I would never want to unlearn what I have learned, even if I could. I listened with my human heart, and at times I know that my face acknowledged their emotions, by displaying dismay and concern, which is contrary to my training as a healthcare professional. These women

⁷⁸ As of July 2017, Erica's surgery for a new cancer on her kidney was considered successful. The women continue to see their oncologists for surveillance on a regular basis.

deserved acknowledgement of their pain and suffering. They needed to know that I heard them. Listening, hearing and feeling are the cornerstones of an empathetic response to stories, or indicative of entering into a relationship with the person telling the story. Through a series of personal reflections, I examined themes such as my sense of the women's expectations of me, paying a debt that I felt I owed, the feeling I was swimming in stories and the nature of scars.

Researcher's reflections: Expectations. There were times between interviews and during the transcription and writing periods when the stories invaded my dreams. Stories have the power to settle deeply in the subconscious, to flutter and dance in unpredictable ways. This was the price I had to pay for the stories I was gathering. In my journal, I wrote:

It is the same dream. I open my eyes to darkness. I reach out to find that I am at the bottom of a dark well. The stone walls are cold and damp. I am blind and shivering. I can hear voices echoing above me but I cannot make out the words. Whose voices are these? What do they want? As the voices grow louder and more insistent, I realize I am awake and staring at the ceiling. (Journal notes, S. Boyko, September 30, 2016)

Researcher's reflections: Paying a debt. During the day in quiet moments, the women's voices continued to echo in my head. In my journal, I wrote:

At one point while changing loads of laundry, I realized that I was carrying on an imaginary conversation with Taryn in my head, explaining some point about her radiation treatment that I wished my colleagues had told her when she really needed to know. I looked up information about her kind of cancer and treatment in my textbooks and online on medical websites to see if I could find a decent explanation of how the radiation treatment could have caused her extreme skin reaction. I felt I owed her (and myself) some closure. (Journal notes, S. Boyko, September 20, 2016)

Researcher's reflections: Swimming in stories. I was drowning in a fiery pool of stories. Day and night the hot words surrounded me. I needed to breathe cool air again. At times, I felt overwhelmed with emotion, sadness, or anger, over the distress some of the women revealed while telling their story. Even the women whose cancer experience began some time ago could still recall and relate the strong emotions that they felt clearly and powerfully. By using the concise haiku form I was forced to examine opposing elements, the heat of words and the coolness of air as I periodically disengaged from the stories.

Haiku: Gathering Stories

*Desperate for air,
I breach the raging surface.
Fiery words surge around me.*

S. Boyko (2016)

Researcher's reflections: Scars that never fade. Each woman described the event and the shock of hearing her cancer diagnosis vividly. Three of the women even went to, or remained at, their work place, although they were clearly affected by the news. Talk about a disorienting dilemma! I wrote in my journal:

Some even recalled the time of day, as well as the date and day of the week they heard the news. I realized then that their memory of the moment they heard their diagnosis (and any subsequent diagnoses) would never fade because of the psychological trauma those three words, *you have cancer*, inflict. (Journal notes, S. Boyko, November 25, 2016)

I tried to imagine what the women were feeling at the moment they heard their diagnosis from their stories and my journal notes in a poem:

Poem: Hearing the Diagnosis

*In that awful moment,
time seemed to suspend.*

*The doctor's words fused and
rushed past me as the room receded.
A cold, dense fog began to roll in,
blinding me and chilling my very soul.*

S. Boyko (2016)

Carrying, Handling and Working With Stories

The women had put their trust in me. I felt an enormous responsibility to handle their stories with care. They are a sacred trust, a gift of connection, and a duty to fulfill. Each story represents a life disrupted. My journal reflections expand on my responses to the women's stories and their personal artifacts, by highlighting the themes of guilt, gratitude, shame, advocacy, hope, and fear.

Researcher's reflection: Taryn. Taryn showed me a scar that resulted from an unanticipated, painful and poorly managed radiation treatment reaction on her arm. In the centre of the image is a lighter surgical scar. She allowed me to photograph her arm (see Figure 11).

I wrote in my journal:

As a radiation therapist, I feel frustrated, dismayed and ashamed that Taryn's physical needs were not met by people who work in the same profession as I did. *People like me.*

She was left to find her own support and figure out how to care for her wound. How could they do that? Why don't they care? (Journal notes, S. Boyko, August 4, 2016)

I was awed by her resilience, grateful for Taryn's trust and inspired by her story. After reflecting on how I felt hearing about her trials and marveling at her indomitable spirit, I created both a drawing and a poem to reflect the figure that I saw in her scar. I saw Taryn arising from her scar, the permanent and very visible symbol of her suffering, to embrace living. I emphasized her bright, light, dancing figure in my drawing.



Figure 15. Photograph of drawing, Taryn: Joyous Spirit by S. Boyko, 2016.

Poem: Joyous Spirit

*Joyous Spirit!
Emerging from the cloud,
Of angry red scars.
Leaping, dancing,
Celebrating life.*

S. Boyko, 2016

Taryn's was the first poem that I wrote. I had not planned to write poetry, just as I had not planned to make any drawings, yet the poem flowed easily from my pen as I looked at the photograph of her scar. I did not know I could write poetry! I was surprised! I created something visible from what was invisible and found that the process expressed my feelings and eased my guilt about her experience, just a little. The power of the arts to enhance knowing and feeling was becoming clear.

Researcher's reflection: Eva. After her interview, Eva recruited other participants to meet with me without hesitation. In my journal, I wrote:

Eva is so feisty, persistent, strong, caring, generous and loyal. She is my cancer dragon! I am grateful for her trust and belief in me and for all her help with my research. She has done so much for other women with cancer as a role model and leader. (Journal notes, S. Boyko, September 4, 2016)

I drew Eva as the “cancer dragon” after her toy dragon mascot, one of the artifacts that she shared with me. She referred to the dragon in her narrative as “a big, dumb, cartoon dragon that I bantered with, taunted and laughed at, whenever I could, which was not very often.”⁷⁹ As contrast, I drew Eva as the cancer dragon. She is a small, fiery and articulate woman who creates a notable presence in any room. Eva allowed me to photograph her artifacts (see Figure 12).

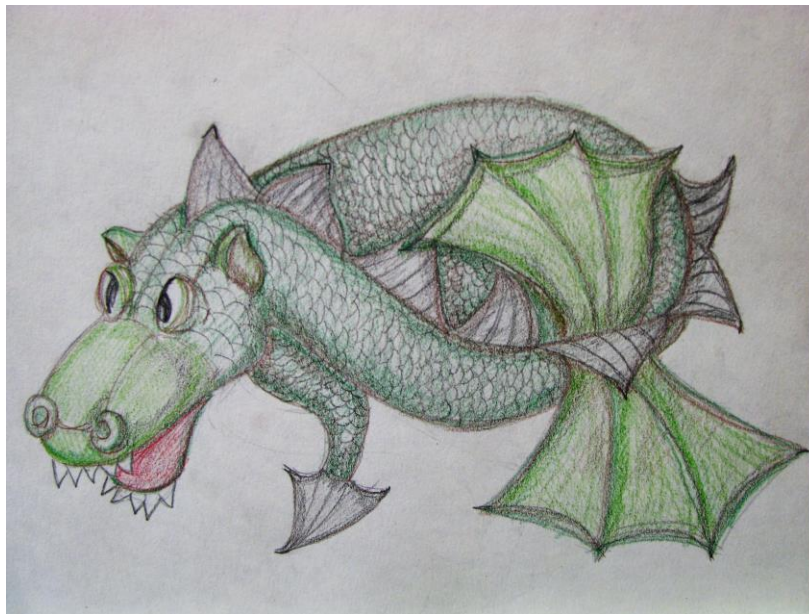


Figure 16. Photograph of drawing, Eva: Cancer Dragon by S. Boyko, 2016.

I created a haiku based on Eva’s story of how she became the dragon boat’s drummer, a leader of women with cancer, both on the water and in the community. As a former dragon-boat competitor myself, I recalled the feel of the breeze on my skin as the boat surged across the

⁷⁹ Eva transcript, p. 1, lines 14-15

water in time with the drum, the flash of paddles rising and falling. I could feel the team's power as each downward stroke cut the water's surface in unison and pulled us forward. I imagined how it would feel for these women to paddle together, sharing a common story of surviving, and living with cancer.

Haiku: Cancer Dragon

*Wind spirit bears us.
Voices rise in chorus,
As her drum beats time.*

S. Boyko (2017)

Researcher's reflection: Erin. Erin's story was delivered with a great deal of anger. The anger was in her tone of voice, facial expressions, body posture and the words she used. I recognized the treatment rooms, hallways and the processes she described, but now I could see them from her vantage point as a patient on the treatment table. Although her anger was not directed at me, I felt scorched. I apologized for her treatment experience. I wrote in my journal:

As a radiation therapist and system insider, I feel responsible and guilty. As a researcher and participant outsider, I feel outraged for her. I carry her anger around with me wherever I go, passing it from my insider self to my outsider self and back again, like a hot coal. I can't put it down. I didn't do this to her! But some of the people who did had been my coworkers, and maybe one of my students was involved! Finally, sick of my indecision, I gripped her anger tightly and took my punishment. (Journal notes, S. Boyko, September 24, 2016)

I carried her anger with me for several days before I decided I needed to acknowledge and examine it by drawing and writing about it in my journal. I did not know how to feel about it. I finally concluded that it is okay to feel angry and ashamed about her experience, too. I asked for

this knowledge; I wanted to know and feel these stories. I needed to learn to deal with my emotions by expressing them.

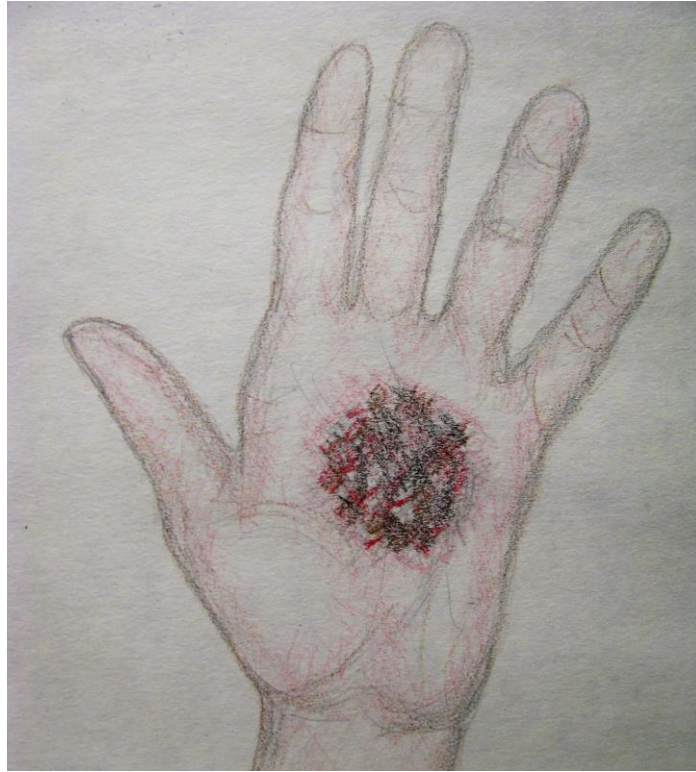


Figure 17. Photograph of drawing, Erin: Her Anger Rages by S. Boyko, 2016.

This time the haiku flowed easily, in relief. Unlike the traditional haiku form, it does not contrast emotions or seasons. It simply is a precise expression of my emotional reaction.

Haiku: Story Gatherer's Lament

*Her words burn
A hole in my open hand.
Her anger still rages.*

S. Boyko (2016)

Researcher's reflection: Loraine. Loraine's interview was like peeling an onion.

Passive and guarded, she responded to my first open-ended question by referring to each question in her copy of the Interview Guide. Was it only that she was nervous? Did she view me

as just another healthcare professional in her story, despite the care I took to introduce myself, my experience in healthcare and talk about what I hoped to learn by hearing stories about experience? Maybe she thought I wanted to hear only positive things, that I wanted her to say that everything about her cancer experience was great. Did she want to please me? Later in my journal, I wrote about my dilemma:

At first, I wondered what I could do with this interview so I could get to her story. Where is her story? How could I salvage this meeting so that I did not waste her (my) time? Maybe if I turned off the recorder we could talk more freely. I redirected us to open conversation and waited for a sign that she was ready to trust me. So, I talked again about myself, the work I had done, my experience with cancer, while watching for a change in her expression. I asked a few general questions about her life and work experience and then I redirected us to her artifacts. I think that her special artifacts, and my interest in them were the key to opening the conversation with me. She appeared to relax a bit and became more animated. Whew! I could resume the interview as a conversation instead of listening to a review of a checklist. (Journal notes, S. Boyko, September 26, 2016)

I took special care when working with Loraine's story to preserve her words because I found her voice to be so fragile it required nurturing. How often did others speak for her? Among her other personal interests, Loraine spoke passionately about feeling especially connected to Sainte-Jeanne-d'Arc or Joan of Arc. She repeated a comment someone made about how her hair style looked like Sainte-Jeanne's hair. I refreshed my memory about the saint, searching historical websites. Joan of Arc, a simple peasant girl, led the French army into battle with the English at the age of 18. She was captured a year later by the English and burned at the stake for heresy by French collaborators in 1431 (Vale & Lanthers, 2017).

Loraine allowed me to photograph her artifacts (see Figure 13). While I looked at the photograph and thought about what Sainte-Jeanne meant to Loraine, I also created a preliminary sketch of the figurine. When I finished and looked at the sketch again, I was startled to realize that I had given the figure in my sketch a face like my own, not the face of Loraine or the unformed, shadowy face of the figurine! My subconscious was hard at work. Who is a crusader?



Figure 18. Photograph of drawing, Loraine: She is my Saviour by S. Boyko, 2017.

With the comment Loraine shared about her resemblance to St. Joan and the figure in the photograph in mind, I created a poem that explores Loraine's (and my own) crusade. Loraine, as a saviour of other women, and me as the women's storyteller, following St. Joan into battle.

Poem: She is my Saviour

*I draw my sword,
and follow her into battle.
The sun lights her hair;
her eyes burn with passion.
She fears only the fire.*

S. Boyko (2017)

Researcher's reflection: Holly. Holly lived through shock, fear, confusion and anger during her cancer experience as she transitioned from an innocent adolescent to a young adult. I get a sense of Holly's spiritual, emotional, as well as cognitive perspective transformation reflected in her tattoo (see Figure 14). I wrote in my journal:

I have never been fond of tattoos but after hearing Holly tell her story and her detailed description of what her tattoo means, I can honestly say I'm a fan! Tattoos tell a story. The tattoo artist is very talented. And he is not finished yet. It's a work in progress, just like Holly's emotional growth. The choice of black ink and shading with white and grey ink makes a great deal of depth in the image. It is a window into her personal perspectives. It is so incredibly beautiful! (Journal notes, S. Boyko, October 14, 2016)

While Holly described her choice of flowers as representing a month⁸⁰ of the year she received her diagnosis and treatment, flowers can also be used to communicate an emotion or sentiment⁸¹, such as, the carnation (fascination and *love*), rose (beauty, *innocence*, and *hope*) and sweet peas (*gratitude* and pleasure). The haiku and drawing I created based on her tattoo are my attempt to convey the impact of both seeing it and hearing about what it means to her, in a way that emphasizes the compelling nature of her story. To view the entire work as a single image, my rendering collapses a very detailed three-dimensional work into two-dimensions. I drew the key words I used in the haiku from the traditional meaning of the flowers in her tattoo, which are in italicized font in the paragraph above. In the haiku form I contrasted her loss of innocence with her personal growth through the hardship that was induced by her illness, and her resilience. The creation of beauty from the field of pain.

⁸⁰ From Birth Month Flowers and their Meanings: <http://www.almanac.com/content/birth-month-flowers-and-their-meanings>

⁸¹ From Canadian Flower Delivery. Flower Meaning: <http://www.canadianflowerdelivery.com/flower-meaning.aspx>

Haiku: Hope Flowers

*Innocence lost.
Love and gratitude flower,
As hope springs to life.*

S. Boyko (2017)

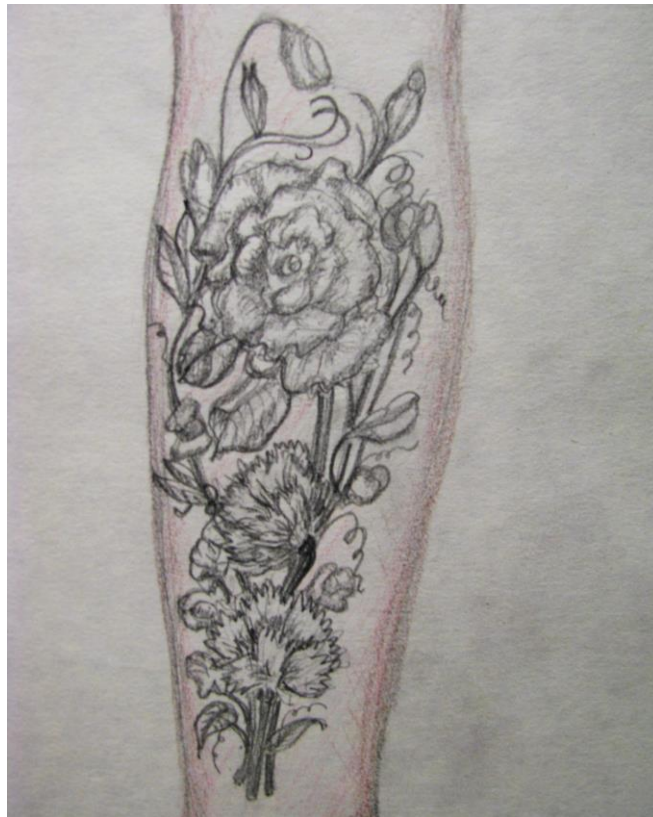


Figure 19. Photograph of drawing, Holly: There is Always Hope by S. Boyko, 2016.

Researcher's reflection: Erica. Erica now imagines two little black clouds following her. While she will always fear the return of her aggressive ovarian cancer, she is now awaiting investigation of the new mass on her kidney. Still, Erica understates her feelings by comparison to the stories of the other participants. She knows that her chances of recurrence of the ovarian cancer are quite high. In my journal, I wrote:

My first impression of Erica was that she is strong and in command of all parts of her life. Yet, it was only today when I heard her whole story, that I understood how much she

knows about how deadly her cancer is and how deeply frightened she is about her ability to manage her own future. And yet, because she is always composed when we meet, I would not have guessed. (Journal notes, S. Boyko, November 30, 2016)



Figure 20. Photograph of drawing, Erica: Two Little Black Clouds by S. Boyko, 2016.

I thought about Erica's black clouds and experimented with smudging pastels across the paper. Although Erica described the clouds as "black," I have represented each one with some variation in their colour. I used blue, grey, white, and black. There are lighter and darker areas, just like the range of emotions in Erica's experiences. Erica said she is thrilled to be retired so she can devote her free time to managing her disease. While I wrote the haiku, I tried to imagine what it would feel like to be hopeful, yet perhaps even to dread the future, at the same time. To look forward to spring and rebirth, and yet to know darkness and uncertainty.

Haiku: Light and Dark

*Two little black clouds,
Follow me into springtime.
Do I dare to breathe?*

S. Boyko (2017)

Final Thoughts: Handling Hot Coals

I recorded my observations, thoughts and feelings in my research journal. In addition to recording my research processes, journaling allowed me to process what I was feeling and explore the impact of hearing the women's stories on me. The journaling process led me to realize a deeper perspective on the complexity of the impacts of cancer and treatment on adult women. My sense of connection with the women also inspired me to write poetry and draw images to express my feelings. I have learned more about the power of the arts to explore emotions, reveal deeper meaning and activate healing powers. I was surprised at how much the women's stories elicited strong reactions and emotions from me. Since I was moved, there is potential for others who hear cancer experience stories to be moved as well. Their cancer experience stories, personal artifacts, and my reflective research journal are fertile and powerful data. What do these data reveal about their experiences? What are the similarities or differences in their perceptions? What were their cognitive and emotional needs? I will address these questions in the next chapter.

List Poems, as described by Franco (2005), are a very accessible way to tell a story and express meaning. They offer "an opportunity to think and talk about sequencing, in the context of a list that is meaningful" to the author (p. 131). My List Poem expresses a range of the emotions I felt during the research process, from most negative to most positive as I perceived them. These words are harvested from my research journal. They document my transformation from an objective to a more subjective research viewpoint and represent the disorienting dilemma that cued my perspective transformation as an adult learner.

List Poem: Embracing the Data

*I felt:
Outraged*

*Frustrated
Scorched
Dismayed
Ashamed
Responsible
Guilty
Awed
Grateful
Inspired
by their stories.*

S. Boyko (2017)

CHAPTER FIVE: DATA ANALYSIS

In the preceding chapters I posed questions related to the value of listening to the illness stories of adults with cancer and whether listening to these stories could promote relationship building and transformational learning in the cancer clinic. What did the illness narratives, their personal artifacts and the collective body-map reveal about the experiences of the women participants? What value did my research journal add to this knowledge? What is the impact on the experience of adults with cancer when their individual characteristics, stages and styles of learning are not accommodated? Analysis of the data I collected helped me to answer these questions. The primary data, which are the women's cancer experience stories, and my reflective research journal notes led me to a deeper understanding of their cognitive and emotional needs beyond what I realized in the literature review and my own experience as a healthcare professional. Their stories provided me with a much clearer window into their reality. Together, the women and I co-constructed their individual narratives. The women's personal artifacts and the collective body map are secondary data. I interpreted meaning from their personal artifacts and the collective body map further in my research journal. I will also discuss the construction of the collective body map, how it relates to the participants and its meaning later in this chapter.

Categories and Themes

The literature reviewed in Chapter 2 pertaining to adults with cancer identified two major categories of needs; emotional and cognitive. Not surprisingly, the six women participants also emphasized their need for emotional support and information about their disease and treatment. However, they also stressed the importance of forming a relationship with their doctors, the key players in their lives with cancer. I will discuss their needs in greater detail and examine

additional themes within these categories that emerged from their personal artifacts and the collective body-map.

Emotional Needs

Similar to the literature, the women who participated in the research needed hope, emotional support and information to help them cope with the upset and uncertainty of their diagnosis and manage their disease, their side effects of treatment and life with cancer. Hearing that they had a diagnosis of cancer created emotional shock and distress that increased their reliance on their doctors. The disorienting dilemma created by their diagnosis emphasized their need for good communication with their doctors; they needed to feel that they were heard and that support was available. Four emerging themes will be discussed related to the emotions the women felt, as well as those they anticipated in their families and friends. The women felt frustration and uncertainty, shock and distress, fear and a heightened sense of responsibility to their families and friends. Even when they might have felt that their own emotional needs were not addressed, they felt responsible to protect those they loved.

Frustration and uncertainty. Waiting for more news about test results, next steps and timely action was difficult for every woman and generated more anxiety at multiple points in their stories. As adult learners, their desire to find solutions for their immediate health crisis was often unsatisfied. For example, Eva and Erin clearly described how hard it was to wait for confirmation of their diagnoses and next steps.

Eva: Sometimes you really have to open your mouth because I thought I'm not going to go the whole weekend, and suffer not knowing if this is going to be good or bad; I remember the day that I said to him [the surgeon], "I

can't wait a month. I'll go absolutely nuts. You have got to realize this is my second cancer.⁸²

Erin: So, the worst thing is waiting to get into the cancer centre because it seems to take forever.⁸³

Shock and distress. Every woman experienced some degree of diagnosis shock, which became their disorienting dilemma as adult learners (Hovey et al., 2012; Mezirow, 1981). The news that they had cancer created a feeling of psychological distress or numbness since most people equate the word “cancer” with death. This dilemma created an urgent need for information to solve this problem and take action. Taryn needed much more internal processing time before she could understand the seriousness of her diagnosis and seek more information.

Taryn: It was when she [the doctor] asked me if my son had a good relationship with his dad and if I had life insurance, I think that was the point that I clued in that this was going to be something that may be a big issue. I think that's when I started to be a little bit shocked.⁸⁴

Eva and Loraine described feeling and displaying intense emotion when hearing the news.

Eva: I left [the doctor's office] and one of the nurses brought me down to Supportive Care because I don't think I could've walked out of the hospital and I saw a psychologist there.⁸⁵

Loraine: I took it quite hard and the doctor actually was pretty surprised, the doctor thought I was pretty upset.⁸⁶

Erin and Holly described experiencing immediate shock or numbness.

⁸² Eva transcript, p. 5, lines 18-19; p. 10, lines 1-2

⁸³ Erin transcript, p. 3, lines 4-5

⁸⁴ Tarn transcript, p. 2, lines 30-34

⁸⁵ Eva transcript, p. 4, lines 38-40

⁸⁶ Loraine transcript, p. 1, lines 14-15

Erin: You can't think because there's just too much coming at you and when you hear the word "cancer," it just means you're dying.⁸⁷

Holly: I don't think I'd processed it. But it was cancer. I don't know how I functioned, but I did.⁸⁸

Erica recalled that she did not feel strong emotion regarding hearing her diagnosis, only a need to act, to arrange for treatment, to solve her immediate problem.

Erica: It was a surprise when I heard the diagnosis because I'd never heard a cancer diagnosis before but I don't recall feeling immense emotion about it.⁸⁹

Aside from Eva, who was directed to a psychologist for emotional support after hearing her cancer diagnosis, none of the women was offered or received professional emotional support at the time of diagnosis. Having adequate emotional support available would have facilitated the women's ability to pause, absorb information and think about the next steps in their care. It would also have been a sign of hope for the future. Fortunately, Loraine was later referred to a social worker for her emotional and financial needs.

Fear of recurrence. All women continue to live with the fear that their disease will recur. This is the dark cloud (metaphor) that follows them. There are times, even years later, when the fear resurfaces by slipping past carefully constructed psychological compartments.

Taryn: Because at this point I was just waiting to die. My cloud had a silver lining.⁹⁰

⁸⁷ Erin transcript, p. 2, lines 7-8

⁸⁸ Holly transcript, p. 4, lines 26-29

⁸⁹ Erica transcript, p. 2, lines 26-29

⁹⁰ Taryn transcript, p. 23, line 36

- Eva: Because even when you're well, I'm well right now, there's not a day that goes by, there's not a minute that goes by, there's a cloud.⁹¹
- Erin: It [fear of recurrence] becomes a distant memory but it is one that's always there and it never goes away.⁹²
- Loraine: I didn't know what was going to happen, because we didn't ask for it [chance of recurrence] the last time because it was too stressful.⁹³
- Holly: It's no longer a matter of *if* I will develop cancer again but *when*. So that's always at the back of your mind.⁹⁴
- Erica: Every time I go in for my appointment to Medium City, it's anxious and now especially when I know I have something else going on. So now I've got two little black clouds.⁹⁵

Sense of responsibility. Partners, family members, and friends could be both an important source of support, as well as a source of stress. Most women described feeling a sense of responsibility to others in their stories. They said that they often felt that they had to appear and sound strong to support and protect their family members and friends emotionally so that those closest to them would not worry about them and worry about the future. Some women also continued to provide daily care for dependent family members during all phases of their illnesses. Taryn, Eva, and Holly, and to some extent Erin, felt the need to support others. For example, Taryn was a single parent to her young son, and she did not have anyone in the city she lived in to call on for assistance when she needed help.

⁹¹ Eva transcript, p. 27, lines 14-15

⁹² Erin transcript, p. 28, line 41

⁹³ Loraine transcript, p. 24, lines 19-20

⁹⁴ Holly transcript, p. 20, lines 9-10

⁹⁵ Erica transcript, p. 17, lines 43-46

Taryn: As the patient, believe it or not, it is very big job to protect your family members from the pain, and your friends, and it's a big job to keep them from feeling helpless.⁹⁶

Eva had a husband and two young children at home whom she desperately wanted to shield from worry and distress.

Eva: You have to find other ways, like I'm talking to you about it because, your family gets really tired of hearing you. They want to believe you're well. And you're going to tell them you're not well?

Researcher: You want to be strong for your family

Eva: That's right.⁹⁷

Holly's family had difficulty coping with her diagnosis. She was instructed by her parents to act as if nothing had happened, which was the way that they coped with distress. Holly could not share her fears and concerns with anyone in her immediate circle.

Holly: His [my father's] reaction was that it didn't really phase him, and I never saw him too concerned. It was more that I just needed to keep going to school and not let anything affect me.⁹⁸

Erin did not want to be a burden to her parents or to her grown children.

Erin: My biggest regret was my oldest daughter kept calling me and I couldn't tell her over the phone, although I had already texted her, 'your mother's got cancer'. When I got home that night, I called her and we talked about it, and then, I think the hardest thing to do was to tell my parents.⁹⁹

⁹⁶ Taryn transcript, p. 4, lines 35-37

⁹⁷ Eva transcript, p. 27, lines 15-21

⁹⁸ Holly transcript, p. 6, line 41; p. 7, line 2

⁹⁹ Erin transcript, p. 2, lines 40-46

The women's stories revealed deep unmet emotional needs that transcend the kind of information about individual experience that can be gleaned from quantitative patient satisfaction survey results. Their stories demonstrate how the current cancer system failed to assess and provide support for their emotional needs: frustration and uncertainty, shock and distress, fear, and the stress of feeling responsible to emotionally support those around them. Quantitative surveys ask patients whether they received support when it was needed. However, the women's stories also tell us what kind of emotional support was needed, and how and when the support could have been offered to meet those needs. If the women's healthcare team had assessed their emotional needs at the time of diagnosis and/or during the treatment phase of their illnesses, they might have been referred to the most appropriate type of ongoing support such as psychologists, social workers and support groups earlier. The information about the women's unmet emotional needs that was uncovered provides administrators and healthcare professionals with an opportunity to make improvements to cancer service in the future.

Cognitive Needs

As adult learners, information was not only critical for the women to cope emotionally, but vital to their ability to navigate their diagnosis, participate in decision making and learn how to manage their cancer treatment. To solve their immediate problems at times of high anxiety, the women displayed information-seeking behaviours, such as asking questions and actively looking for more information outside their therapeutic relationship. They also mentioned monitoring (actively gathering) and blunting (avoiding) information behaviours at different times during their illnesses. The women utilized mainly assertive or passive communication styles, rather than aggressive styles, when interacting with their doctors and other members of the healthcare team. Some learning styles, such as converging or assimilating, that are most like

doctors' styles, were better suited to gathering and processing medical information than other styles. Divergers and accommodators were more likely to feel that their needs for information were unmet. By understanding how individual learning and communication styles can influence the development of interpersonal relationships, and affect patient cognition and well-being, healthcare professionals might find ways to address these more effectively in future.

Information seeking behaviours, learning, and communication styles. Taryn and Erica, who had the highest level of education and had held positions of the greatest responsibility, were very active in information seeking and direct or assertive in their communication with their doctors from the outset of their illnesses. Their learning style was converging.

Taryn: I was appreciative of being able to know the statistics and know the process and know exactly what everything meant because I could prepare him [my son] and I could make sure that it was never, “nothing and everything was going to be just fine”; I do appreciate that I had that information right from the beginning.¹⁰⁰

Erica: I'm a great Internet person so as soon as I knew I was getting a hysterectomy, I looked that up; What's been nice is Dr. D's shown me the results of everything.¹⁰¹

Holly's learning style was assimilating. Although many doctors are also assimilating in learning style, because of her youth many healthcare professionals did not take the time to assess her informational and emotional needs. Although anxious to know more about her cancer and treatment, she lacked the experience and self-confidence to ask questions. Eva, with a diverging

¹⁰⁰ Taryn transcript, p. 3, lines 21-25

¹⁰¹ Erica transcript, p. 3, lines 11-12; p. 6, lines 33-34

learning style, was more dependent on her relationship with her doctors for information and her needs were less likely to be met when her doctors were both convergent in learning style and aggressive in communication style. Erin and Loraine were both accommodating in learning style and passive in communication style, tending to rely on their healthcare professionals for information. Their information and emotional needs were often not met by their healthcare team. Loraine's ability to gather information was further complicated by her learning disability.

Experiential learning. Kolb (1984) emphasized how important it is for adults to learn through their experiences. As the women faced new challenges, a cycle of thinking, asking questions and gathering more information helped them change how they viewed their situation and prepared them to become more active in their own care. They learned about their cancer, treatment, and managing their side effects by feeling pain, fatigue, and anxiety. The women needed time to reflect on new information and reorganize their beliefs to make decisions that allowed them to solve their own immediate problems. They gained confidence and were more able to anticipate their own needs. Eva and Erin gained confidence and knowledge through their experience of cancer and the support of peers.

Eva: After that I paid attention because of my experience. Because we knew, it wasn't as terrifying as the first time because the first time I didn't know what they were doing with me; I was more confident the second time around.¹⁰²

Erin: If I have any questions, there's always someone in the room [peer support group meeting] that either knows of a place or has been through it and

¹⁰² Eva transcript, p. 11, lines 18, 20, 27-28; p. 6, line 6

says, “Call so and so.” Or they’ll look into it for me and then come back with an answer.¹⁰³

Holly gained knowledge, confidence, and voice through her experience and, more formally by becoming a healthcare professional.

Holly: I went over a year without being seen [by the oncologist]. I ended up writing a letter to Large City hospital asking why I was being refused service through Telehealth and filling them in on everything, including copies of emails. And all of a sudden, I got a phone call from Telehealth that he [her oncologist] was going to see me.¹⁰⁴

Loraine is still very much a passive participant in her care but has resolved to ask her doctors for more information in future. She has questions about her health and wonders about what to expect in future.

Researcher: Did they tell you that was a side effect?

Loraine: They didn’t tell me that, no.

Researcher: Is that something you want to ask your doctor about?

Loraine: I think I should, I think it would be a wise decision to ask.

The women learned to recognize their symptoms and gained the knowledge and confidence to ask questions that would help them manage their own care.

Asking questions, reflection, and dialogue. Opportunities to ask questions, reflect, and to participate in an open dialogue, actions Mezirow (1981) states are necessary to adult learning, were highly valued but not always available. Often, essential information about their care was transmitted but there was not enough time during the encounter with their doctors for the women

¹⁰³ Erin transcript, p. 24, line 47; p. 25, line 2

¹⁰⁴ Holly transcript, p. 20, line 44; p. 21, line 5

to reflect, formulate questions and get answers to those questions. Being proactive and seeking information beforehand allowed women to maximize the time they spent with their doctors, Taryn and Erica expected to and actively participated in conversations with their doctors.

Taryn: If I had a family physician that I had some rapport with when the node in my axillae popped up, if I had gone in and said, I found this and I think it's melanoma I think they would've been more likely to believe me than the clinic doctor or the plastic surgeon that I happened to have contact with.¹⁰⁵

Erica: When you have a diagnosis of cancer, there's one person I need to talk to and that's the oncologist, and when I knew I was having surgery it was the gynaecologist.¹⁰⁶

Eva, Holly, and Erin were more passive in conversations initially but became more active once they gained knowledge and experience.

Eva: There was no stupid question you could ask him; the first time I had cancer it wasn't like that. I was told very bluntly. There were no questions I could ask.¹⁰⁷

Holly: I would like to have had been given the opportunity to ask questions. What do you mean "the biopsy"? Like, what is a biopsy? What do you mean by "tumour"?¹⁰⁸

Erin: Sometimes depending on what the problem is, I'll actually ask Dr. D. And she's stopped saying, "You should ask your [family] doctor." She'll

¹⁰⁵ Taryn transcript, p. 29, lines 5-8

¹⁰⁶ Erica transcript, p. 9, lines 28-30

¹⁰⁷ Eva transcript, p. 13, lines 5-6; p. 4, lines 33-34

¹⁰⁸ Holly transcript, p. 22, lines

answer me, whereas the other one [oncologist] was, “Well, that’s for a [family] doctor to answer.”¹⁰⁹

Loraine continues to be passive in conversations with her doctors, waiting for information to be offered and to be asked questions by the doctor.

Loraine: They [surgeon and radiation oncologist] both talk to us and I'm just listening to the doctor.

Researcher: Okay. Sometimes the doctor's talking directly to your mom and not to you?

Loraine: And not to me. Then the doctor will ask me, “Do you have any questions, what are you feeling right now?”¹¹⁰

Customized information. Similar to Zilinski’s (2010) findings, the women said that their information needed to be customized to just the information she needed, in just the amount she wanted, when she was ready to receive it, and in ways that best suited her learning style.

Taryn: I think that I knew that I didn’t want to know until I had time to process it myself. Once I started reading about it, it wasn’t a pleasant diagnosis.¹¹¹

Eva: My perfect solution would be, talk to me, tell me what’s going to happen next, not 8 months from now, tell me what’s going to happen now until I finish this.¹¹²

Erin: They made it mandatory that you have to go to radiation education and chemo education [group classes]. I had already had quite a few radiation

¹⁰⁹ Erin transcript, p. 25, lines 2-7

¹¹⁰ Loraine transcript, p. 15, line 35; p. 16, line 2

¹¹¹ Taryn transcript, p. 3, lines 12-13

¹¹² Eva transcript, p. 21, lines 19-21

treatments and I'm already getting the chemo. Why do I need education about it now?¹¹³

Loraine: People with a learning disability have more difficulty. I understand in a way that is different. So, if someone explains it differently I would understand it.¹¹⁴

Erica: As soon as he gave me the diagnosis of clear cell, I looked it up [on the Internet], which was not a good thing to do because it is a rare, aggressive cancer and the prognosis from the material on the Internet is not good.¹¹⁵

Eva, Erin, and Erica described needing information specific to their care and finding generalized information and group learning sessions as less helpful.

Eva: When I had the chemo session, I went in and they told me [about chemo], and I was so terrified.¹¹⁶

Erin: What am I going to do with the binder? The information is very basic and generic—I haven't heard of anybody saying, "Oh, this was really good information" because it wasn't.¹¹⁷

Erica: It [the binder] was somewhat helpful. I mean, I didn't know about any kind of teaching sessions or any kind of workshops I could attend.¹¹⁸

Taryn and Erica were quite adept at seeking out additional information on the Internet.

Taryn: So at the time of seeing the oncologist I had already done a lot of research on my own and that's probably when I got the most information and the

¹¹³ Erin transcript, p. 6, lines 12-15

¹¹⁴ Loraine transcript, p. 27, lines 24-26

¹¹⁵ Erica transcript, p. 3, lines 13-16

¹¹⁶ Eva transcript, p. 21, lines 14-15

¹¹⁷ Erin transcript, p. 4, lines 10-12

¹¹⁸ Erica transcript, p. 13, lines 40-42

most insight into how things are done here in Canada, which drugs are available, what kind of steps that are taken, it gave me insight into what to expect and when to expect decision making points.¹¹⁹

Erica: I'd bring my iPad in with me if I had questions that I wanted to ask them [the doctors] but I think I was well-informed so nothing they told me has ever been a surprise. Everything that happened was as I read it. There's a lot of forums you can go on and there's an ovarian cancer forum that I'm still on. Women talk about exactly what's happened to them.¹²⁰

Holly received very little information throughout her illness and did not know how or where to find more.

Holly: I was given one book on what radiation treatment was and what the side effects were for every part of the body. So, I read that book from start to finish. The book was not site-specific. It was generic. And I did not understand that radiation affected right where it was targeting. That was overwhelming; As far as any classes or support groups or stuff like that, I wasn't offered anything.¹²¹

Loraine accepted the information she did receive and did not look for more by asking questions.

Researcher: What kind of information have they given you about what you can expect now that you don't have a thyroid anymore?

Loraine: They've never given me any information about that.

¹¹⁹ Taryn transcript, p. 4, lines 6-10

¹²⁰ Erica transcript, p. 8, lines 19-24

¹²¹ Holly transcript, p. 14, line 37; p. 15, line 4

Researcher: I think that's something [always being thirsty] that you need to ask the doctor.

Loraine: [Nodding] It would be a wise decision [to ask].¹²²

The women's ability to learn about their illnesses, problem-solve, and manage their healthcare was greatly affected by their anxiety about the future. When healthcare professionals did not recognize and meet their emotional and cognitive needs, their anxiety increased, and their learning was delayed and complicated while they tried to find the information and emotional support they needed elsewhere. Women who were converger/assimilator in learning style and assertive in communication style, like those of most doctors, could acquire the information and support they needed more readily from their doctors or from other sources. Women who were diverger/accommodator in learning style and passive in communication style often did not receive the information and emotional support they needed from their doctors and found these supports from other healthcare professionals, friends, or peer-led support groups. Their cognitive behaviours and the opportunities they had for learning impacted on their ability to cope, problem-solve, make decisions, and to achieve perspective transformation. The emotional impact or disorientation of cancer causes an intense need for information about cancer, treatment and the likelihood of survival. The shock and fear of a cancer diagnosis can impede an adult's ability to learn, process information and make decisions about care. The impact of human emotions on learning in illness should be explored further.

Relationships

The women's cognitive and emotional needs were tightly entwined with the relationships they had with their doctors. The importance of this relationship came through strongly in their narratives. Back (2006) and the National Cancer Institute (2015) suggest that patients regard

¹²² Loraine transcript, p. 9, lines 16-18; p. 26, lines 34-37

their oncologists as one of the most important sources of psychological support because the oncologist is the person they have come to trust and expect to take care of them. The themes that resonated consistently with the women were not only the importance of receiving information and emotional support (or hope), but how important it was to receive it from their oncologists and other doctors in the context of their therapeutic relationship. However, there were instances where their doctors did not consider their cognitive and emotional needs. Both the RCPSC and the CFPC standards mentioned in Chapter 2 describe the role of “Communicator” as an expectation for family doctors and specialists, such as oncologists and surgeons. This role requires doctors to prioritize the patient’s preferences and demonstrate respect, empathy, and compassion in interactions. However, neither role statement specifies that the doctor is expected to provide psychological support.

Role expectations of doctors. Kiely et al. (2004) discuss the influence of role expectations for teacher and learner in adult learning. Does the teacher expect to be the expert who transmits information to the learner? Does the learner expect to be a receiver of information or a partner in learning? Eva, Erin, Holly, and Loraine viewed their doctors as the experts in their care and not as partners. They depended on their doctors for both their informational and emotional needs.

Eva: “I’m a surgeon, let me do my job, and I promise you you’ll be okay.” He took all the stress off me at that moment because then I handed it to somebody else. He took on that job. And he told me he was going to take care of me, we were going to do it quickly, he knew my history, how frightened I was to have cancer again.¹²³

¹²³ Eva transcript, p. 4, lines 17-20

Erin: You've just told me I've got cancer. It's still the big C word. And you don't get any hope out of the doctors because they're like, "Well." He basically put his hands up in the air and said, "There's nothing more I can do for you."¹²⁴

Holly: At this point, I still had no idea about what cancer treatment was for different types of cancers and what was the best option and I didn't look into the options. I didn't educate myself before making the decision. I think I kind of trusted my doctor instead. "Whatever you think I need to do, do." And we signed the papers that day.¹²⁵

Aside from her family doctor with whom she indicated she had better interactions with most recently, Loraine did not distinguish between her doctors in terms of her relationship with them in any way in her narrative. She referred to her doctors with the pronoun, "he" consistently throughout her story. They were faceless and colourless entities, always represented as authority figures. Loraine followed their instructions and advice completely.

Taryn and Erica viewed their doctors as partners in their care and stated that they did not expect their doctors to meet their emotional needs. They also actively sought information and support outside the therapeutic relationship, right from the time of diagnosis.

Taryn: The physician does a lot of the science, knows the treatment, can write the orders, knows how things are going to progress, can give you information on that; I really knew the expectation of going to see the physician was that you got the science, you got the medicine, that wasn't really the place

¹²⁴ Erin transcript, p. 4, lines 2-5

¹²⁵ Holly transcript, p. 8, lines 1-5

for me to download my emotions.¹²⁶

Erica: I found all of them [doctors] to be amazing. They're all detached but they all cared. That's what I sensed. Do we spend a lot of time talking? No. But do I get what I need to out of them? Yeah.¹²⁷

The information and emotional support provided by doctors was viewed as most helpful when the woman said her doctor actively listened, answered her questions and responded to her story with empathy. Taryn, Eva, and Erin described contrasting instances in their stories where the relationship that they had with one or more of their doctors was much more supportive in terms of the information and emotional support they received than the relationship they had with other doctors.

Taryn: Now it's not quite the same as it was in Large City, because my family physician in Large City, if I was having an issue and I called, they'd be like yeah, can you be here by 2:00? Whereas here [Small City] it's, well can we make you an appointment for next week or we'll make you an appointment in 3 weeks. It could just be that it could take a little bit more time to build that rapport, that when I call for an appointment it's because I need an appointment. It's cancer related.¹²⁸

Eva: When I had to go for chemotherapy [the first time] the oncologist that I had was very blunt, he was not understanding, he would not look me in the eye. My oncologist this time around, Dr. D, is a wonderful man, understanding, caring.¹²⁹

¹²⁶ Taryn transcript, p. 6, lines 31-33; lines 37-39

¹²⁷ Erica transcript, p. 8, lines 10-12

¹²⁸ Taryn transcript, p. 29, lines 28-32

¹²⁹ Eva transcript, p. 4, lines 24-25

Erin: From what I understand now, he's [the medical oncologist] not really known for having the best bedside manner or his way of talking to people is very blunt and very, there you go and have a happy end, see you later. I'm onto my next one; Another two weeks go by and I finally get to meet the [radiation] oncologist, and very lovely lady. I've got high praises for her, she's a wonderful doctor.¹³⁰

The women expected to form their primary care relationship with their doctors. Direct communication was an important component of this relationship. The ideal visit with their doctors would have meant that the women were invited to tell their illness stories and express their fears, have their most pressing questions answered, offered a referral to a psychologist or social worker for their emotional needs (if they wished) and to be offered hope. They would be offered a relationship of care.

Role expectations of other members of the healthcare team. Information and emotional support provided by other healthcare professionals in the narratives, such as psychologists, nurses, and radiation therapists, was also valued because of the quality of the therapeutic relationship or sense of connection that the women formed with these professionals, especially when the woman did not feel a connection to their doctors. Because she was very anxious, Eva depended on her psychologist for emotional support the first time she had chemotherapy treatments.

Eva: I saw a very good psychologist. He was with me for all of my treatments. He would see me before my chemotherapy and he would calm me down so that the drugs would come in and do their job.¹³¹

¹³⁰ Erin transcript, p. 13, lines 4-7; p. 5, lines 9-11

¹³¹ Eva transcript, p. 4, lines 39-42

Holly found the information and support she needed from other healthcare professionals such as a radiation therapist and a physiotherapist when she could not build relationships with her doctors.

Holly: Pretty much every single day, the same female therapist would come and get me out of the waiting room. I looked for that face every single day. Every day, she'd ask me how things were going, always be talking to me, and was very calm. She had a very calming effect. Once she called my name and we were going in [the treatment room], I don't think I was anxious anymore; It wasn't until I was in university that I got connected through the [education] program with the physiotherapist at Small City cancer centre. She showed me different exercises to try and retrain muscles to do different things, to put my shoulder back into position.¹³²

Erin relied on her chemotherapy nurses for information and support.

Erin: One thing I'll say for the chemo nurses, they are absolutely God-sent angels. The care that you get in there is just beyond.¹³³

As demonstrated in the women's narratives, the need for information and emotional support within the context of their interactions with their healthcare team featured prominently. The relationship each woman had with her doctors greatly influenced her perception of her experience and could enhance her ability to cope during difficult circumstances. When they were not able to form a therapeutic relationship with their doctors, some women turned to other healthcare professionals, friends, or other women with cancer for support. The women's

¹³² Holly transcript, p. 10, lines 26-27, 31, p. 19, lines 31-31, 42-43

¹³³ Erin transcript, p. 7, lines 33-34

narratives emphasize the importance of the human connection to their ability to cope emotionally during illness.

Change of personal perspective. By telling her illness story each woman had the opportunity to reflect, reframe, and compose her experience story orally which may have provided her with new insights into her own illness. For example, both Taryn and Eva were able to find something positive in the darkness of their illness experience.

Taryn: In hindsight, I am very fortunate that I had that eight months that I lived here with my mom, and helped her go through what she went through. The funniest, the most ironic part is I would have never had that opportunity had I never had cancer.¹³⁴

Eva: So it [the genetic predisposition] brought some family back together. It was really weird but there are some good things sometimes that come out of this bad thing.¹³⁵

By interpreting their past experiences with cancer from their current points of view, the women were able to draw connections between these life events and their feelings. These insights were not always apparent to the women during their illnesses. Knowing how things have worked out in their lives, despite experiencing very challenging circumstances, provided the women with a different perspective on their lives. While Erin, Holly, and Loraine did not describe realizing positive insights about their cancer experience as Taryn and Eva did, they are resolved to become more involved in their healthcare by asking questions and gathering more information about the indications of recurrence and living with the side effects of treatment. Erica is very actively engaged in managing her new cancer. The women's transformation from

¹³⁴ Taryn transcript, p. 26, lines 13-16

¹³⁵ Eva transcript, p. 9, lines 8-9

their initial perspective or role of cancer patient, to the role of cancer survivor, was fortified by information and emotional support. A transformation of perspective signifies that a woman possesses greater knowledge and the confidence to engage in making informed decisions about her health.

Peer-led support groups and empowerment. In addition to the information and psychological support that they may have received from healthcare professionals, families, and friends, the women also found other ways to meet their emotional, cognitive, and relationship needs. Even when their basic needs were being met, they found benefit, or self-empowerment, in seeking both live interactions and virtual connections. Taryn, Eva, Erin, Loraine, and Erica sought support or self-empowerment by joining peer communities. These communities have allowed them to gain information, find emotional support and hope, and influence system change. Taryn had been a member of a professionally-led support group early in her treatment process to access services for her son. Eva, Erin, and Loraine are currently active members of a peer-led support group. These groups share information that is based on the members' personal experiences of diagnosis, treatment and living with cancer, as well as afford emotional support by participation in the group (Butow, Kirsten, et al., 2007; Grande et al., 2006; Krizek et al., 1999). Taryn and Erica were, and still are, members of online peer support communities that share information specific to their type of cancers and treatment. These groups also profile success stories and the latest research, which both women find hopeful and encouraging.

Taryn, Eva, and Erica are also committed to helping others navigate the intricacies of having cancer by becoming advisors to the regional and/or provincial cancer system. By participating on institutional advisory councils, "patients may participate in institutional quality improvement projects, help redesign service delivery processes, ... and help develop educational

programs for hospital staff” (Institute of Medicine, 2012, pp. 7-10). Taryn and Holly have spoken to other healthcare professionals at educational rounds and conferences about their own cancer experiences to encourage awareness and promote changes in practice and the education of healthcare professionals.

The importance of the women’s relationships with their doctors to meeting their emotional and cognitive needs, and to their satisfaction with their experience was more evident in their narratives than in the cancer education literature. There were instances where the healthcare professionals involved in their care needed to do more to assist the women to find information and emotional support when they needed it most. Likewise, it is surprising how empowering it was for these women to join a peer support group or connect with peers online to find the information and support they needed.¹³⁶

Additional Themes From the Literature: Age, Gender, and Location

According to the cancer patient education literature, factors such as a person’s age, gender, marital status, location, education, and place of work are factors that are often considered to affect a cancer patient’s experience of care (e.g., Butow, Kirsten, et al. 2007; Ehemann et al., 2009; Grande et al., 2006; Krizek, et al., 1999). By virtue of their gender, the women were more likely to expect and value emotional support, join peer support groups, and tell their experience stories of illness than men. Based on these literature, while identifying predominant themes such as the women’s emotional and cognitive needs, I also considered other factors such as the woman’s age, the gender of her doctors and the cities (locations) where she received her care. I expected to identify similar factors in the women’s narratives because of my experience working

¹³⁶It was helpful to construct a summary of the codes and categories arising from the women’s narratives in table format during the analysis process. This summary is available in Appendix H, Summary of Codes, Categories, and Descriptive Statements. Similarly, the women’s information seeking behaviours, needs and expectations are summarized in Appendix I, Summary of Participant Behaviours, Needs, and Expectations.

in the cancer system. However, aside from Holly, who believed that she was not taken seriously because of her young age at diagnosis, there was no clear pattern to support further consideration of these factors for this group of women. The women did not point to the gender of their doctors or to the cities in which they received care as factors in their stories.

Holly was referred to a very large cancer centre for specialized care and her unique cognitive and emotional needs were not recognized, assessed, or taken care of. Erica travelled between small, medium, and large cancer centres for various aspects of her diagnosis and treatment. She was very prepared with knowledge about her cancer and had high expectations for her care. Erica was more satisfied with her experience of care. Factors related to the doctors and the women, such as their learning/communication style or role expectations were more important to their overall experience than the gender of their doctors or the cities in which they received their cancer diagnosis and/or treatment.

Themes Emerging From Arts-Based Personal Artifacts

The personal artifacts that four of the women shared during their interviews added colour and depth to their stories. Not only did the artifacts serve as a conversational focus, they also illuminated aspects of the women's narratives that were important to them. By presenting and describing these arts-based artifacts, the women introduced powerful images to their narratives that became meaningful metaphors.

Eva: Fight and empowerment. Eva's personal artifacts reinforced the concern she expressed in her narrative about running out of time with her family (the importance of family), and the need to fight the dragon (cancer) with other women warriors (women with cancer) in both her dragon boat and peer support groups. The metaphor, fighting cancer and the empowerment theme were further reinforced in her poem, *Warriors in Pink*. Eva's artifacts

speaking to empowerment of herself and other women with information and emotional support. The drawing, *Cancer Dragon* (see Figure 16) further embodies the metaphors, battle and fight, that Eva used when she spoke about her experience.

Loraine: Dependence and protection. Loraine's personal artifacts, which were religious figurines, reflected her spiritual beliefs and her admiration for strong female characters such as the Virgin Mary and Sainte-Jeanne-d'Arc. The poem, "She is my Saviour" (see p. 109) explores the relationship between her spirituality and women of power. The "saviour" she refers to could represent one of the many women in her life, such as her mother, her female friends and associates at work or women in her peer support group, all women she depends upon a great deal for information and emotional support. "Saviour" is also her metaphor. Loraine's artifacts are a cry for understanding, compassion, and support from her healthcare professionals. She needed a "saviour"; a protector or an advocate to support her. Fortunately, her mother and friends tried to make sure that she had enough information to manage her cancer and cope emotionally by asking questions for her. Loraine's artifacts represent her need to be taken care of spiritually, emotionally and cognitively.

Taryn and Holly: Body art, transcendence, and hope. Taryn and Holly's personal artifacts were their body art. Taryn's body art was unintentional, since it was a very visible and unsightly scar resulting from her radiation treatment. She is very comfortable with her scar, describes it easily if asked by strangers and does not hide it under a long sleeve. My interpretation of the figure I saw in her scar, the "Joyous Spirit" poem and drawing (see Figure 15), aligns with her arduous experiential learning story of how she has transcended living with the threat of a deadly disease to live a grateful life of joy. Her metaphor is "transcendence."

Holly's body art, a tattoo, was very intentional. She designed it as a celebration of her cancer-free status and its floral motif depicts innocence, love, gratitude and hope. She displays it proudly and does not hesitate to tell her story when asked about it by strangers. Holly's metaphor is "hope." I interpret her tattoo as a symbol of her personal growth from teenager to young woman, as well as from an adolescent with cancer to a young adult cancer survivor and confident healthcare professional, her experiential learning journey, in the haiku, "Hope Flowers" (see p. 111).

The themes of empowerment, trust, dependence, transcendence, hope, and learning from experience feature in the women's personal artifacts. Their personal arts-based artifacts highlighted the contrast between their fears, despair and pain, and the joy, celebration, and triumphs in their lives. The artifacts also illustrate the themes derived from their narratives, further depicting full and dynamic lives that were disrupted. As anticipated from the literature, the women experienced shock, fear, anxiety, a heightened sense of responsibility, and conflicting role expectations. Remarkably, they also demonstrated needs for physical and emotional support, information, advocacy, and understanding that were more closely intertwined than the literature suggests. Their disorienting experiences were overcome with determination, hard work and persistence. The next section of Chapter 4 discusses how a body-map, another arts-based modality, was used to visually represent the women's experience and further illuminate the themes of both psychological and physical trauma, the negative side of cancer stories that are often not apparent.

What Lies Hidden: The Collective Body Map and Themes

Unlike the practice of modern medicine, which Kuipers (1989) describes as objectifying a person by focusing attention solely on his or her disease, thus separating the body from the

person, this arts-informed inquiry is meant to be a wholistic¹³⁷ work. I describe whole person care as care that places equal emphasis on caring for both the body and mind. According to Hutchison, Hutchison, and Arnaert (2009), the whole person care concept is antithetical to the practice of modern medicine. I gathered the women's storied experience to convey an understanding of the experience of the entire person with cancer, not only of her physical disease. To portray their combined experience visually, I created a collective body map.

Body maps are visual representations of a person's psychological or somatic (physical body) experience (or trauma); they are a way of making what is invisible, visible. In this way, body maps can represent a knowledge that is truly embodied, known or experienced in the individual. Although adult education and illness-related studies are published in journals and presented at professional conferences, I wanted the women's experience stories shared in my research to have greater impact by including visual images. The women expect me to use the stories they entrusted me with to make a difference in the way people with cancer receive care. Based on my review of the arts-based literature (Allen, 2014; de Mello, 2007; Gastaldo et al., 2012; Skop, 2016), creating a visual representation of their experiences to add to their stories has the potential to do this. I already carried their experiences around with me in my role as the story gatherer. Their physical and emotional scars had a profound effect on me. I wondered, what would their stories look like if they were superimposed on each other, like they were in my head and on my heart? After several rough sketches, I began to envision a life-sized collective body map. My participants' experience of cancer is both physical and psychological. The women came forward because they wanted to "tell" their stories. Although intrigued (and amused) by the concept of body-mapping, when I showed them my life-sized sample and explained its purpose, most women said that they did not feel that they needed to reflect on, or to "show" their

¹³⁷ Wholistic, a variant spelling of holistic, is used preferentially to reflect inclusion of the whole person.

experience as deeply. However, they all expressed interest (and curiosity) in seeing the finished product that would include their ideas and suggestions presented symbolically.

An avatar is “an embodiment (as of a concept or a philosophy) often in a person” (Avatar, 2017, para. 2). I named the life-sized collective body map that embodies the women’s experience “AVAtar.” “AVA” is emphasized in capitalized font because it is a commonly used woman’s name. She was my visual reminder, inspiration, or muse, while I wrote this dissertation. She reminded me of the women’s stories and my emotional responses to them. The women were rendered mute and deaf to further stimuli in varying degrees when their diagnoses were pronounced. Their fields of view either shrunk down to tunnel vision, like Erin and Holly, or receded briefly, like Eva. Like the women at time of diagnosis, AVAtar cannot see, hear, or make sounds. She communicates visually, however, her message will vary according to the receptivity, experience and knowledge of the person who views her.

AVAtar is also my visual metaphor for the emotional impact of hearing each woman’s cancer experience story on me, as researcher, teacher, and healthcare professional. She represents what I have come to know of their embodied knowing, which is the overwhelming physical and emotional impact of cancer and treatment. By seeing the overlay of physical and emotional experience, I “knew” or understood their experience in a totally different way than I did as a healthcare professional, when I had gazed at their superficial body features, or detailed images of internal structures from x-ray images and CT scans on the computer. The physical representations on AVAtar’s surface now had depth, texture, and colour. The physical features also had *voice*, as I could hear each woman re-telling that part of her story as I looked at each scar and the representations of each treatment modality. In addition to being visible, thickened tissue that remains after damage to the skin heals, a scar can also be “a lasting moral or

emotional injury” (Scar, 2017, para. 4). The women’s emotional trauma, worries and concerns are also made visible by AVAtar. These scars tell a story of lives that were traumatized and forever transformed. The women’s experience could become anyone’s experience, as well as my experience. AVAtar created a disorienting dilemma for me. I asked myself: “How would I feel if this happened to me?”; “What would I do if this happened to me?”; and “Why not me?” many times. I am very grateful for my health.

Body Map: Beginnings

The outline had two tracings of myself, one overlaid on the other. The figure in the background (with brown hair) represents me as the researcher, separate from the women’s collective figure (without any hair) in the foreground. Both outlines were painted in different flesh tones to set them apart from each other. “Eva said that she liked the way I had separated their collective figure from my own figure” (Journal notes, November 29, 2016). The women’s figure in the foreground has textured two-dimensional internal organs or “guts” (brain, heart, lungs, liver, stomach, small and large intestines) as well as a thyroid gland, a uterus with fibroids, and two ovaries and two uterine tubes. I created these internal organs by cutting pieces of coloured fabric into approximations of human organ shapes, sizes, and colours, comparable to those that I viewed in an anatomical textbook. I chose simple, non-medical materials of different textures like canvas, fabric, cord, braid and wool that were easy to use, familiar and available to anyone. I drew, painted and sewed, all methods of engaging with the figure by hand (see Figure 21). The resultant female figure is simple and raw, as I intended. It is as simple as an anatomical drawing in a medical textbook, yet it is raw, stripped and exposed like the women’s experience of cancer in their stories.



Figure 21. Photograph of AVAtar: Beginnings.

The First Treatment Modality: Surgery

To create the body map from the outline of the figure, I added representations of the women's treatments and their physical experiences to AVAtar, beginning with surgery since each woman's experience story began with some form of surgical, or otherwise invasive type of biopsy.¹³⁸ I used segments of knotted black cord, like the black thread used for surgical sutures, on AVAtar's surface to indicate the location and number of the surgical scars that are visible on the surface of their bodies, most of which are usually hidden by clothing and not visible to us:

¹³⁸ Canadian Cancer Society. <http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/surgery/?region=on>

1. Taryn's scars, both visible and non-visible, are found on her right forearm, her right upper arm (excisional and radiation), three small scars (excisional) on the right side of her chest, and another scar along the left side of her jaw line.
2. Eva's story contributed non-visible scars that were horizontal on her lower pelvis (hysterectomy), across her left upper chest (mastectomy) and left armpit (axillary node dissection), plus two scars across the left side of the pelvis (two colectomies). Eva referred to her collection of permanent, visible (to her) reminders as "my battle scars."¹³⁹
3. Loraine's scar is a visible semi-circle at the base of her neck (total thyroidectomy). While she found the biopsy and her surgeries to be painful experiences, Loraine described her semi-circular scar in a positive way by saying, "I didn't have to go to a tattoo parlour and I got a smile!"¹⁴⁰
4. Holly has non-visible scars on the left side and back of her neck and shoulder (trapezius muscle resection), and along the left side of her torso (muscle and skin relocation). Referring to the time of her surgery, she said, "The scars are what got me. I had a lot of issues with body appearance because of the scars." Five years later, Holly reveals her change of perspective about her scars when she said, "My scars don't bother me anymore. I own them. Like, they are what makes me, me."¹⁴¹
5. Erica's non-visible scar is also horizontal on her lower pelvis and the representation of her pelvic scar on AVAtar is shared with Eva.

(See Figure 22.)

¹³⁹ Eva transcript, p. 28, line 16

¹⁴⁰ Loraine transcript, p. 21, lines 24-25

¹⁴¹ Holly transcript, p. 18, lines 11-12; p. 22, lines 30-31



Figure 22. Photograph of AVAtar: The first treatment modality: Surgery.

The Second Treatment Modality: Radiation

Radiation is invisible, makes no sound, has no smell and creates no sensation as it passes through your body.¹⁴² It can cause reddening or burning of the skin and a variety of side effects, both temporary and permanent, according to the part of the body that is being treated and the amount of radiation that is given. Both the superficial and internal side effects are usually well-managed by the radiation oncology team with medications when needed.

¹⁴² Canadian Cancer Society. <http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/radiation-therapy/side-effects-of-radiation-therapy/?region=on>

To make the side effects of treatment visible, red netting was tacked in place on AVAtar to represent the areas treated with radiation for:

1. Taryn, over her right upper arm scar
2. Eva, over her left upper chest and armpit scars
3. Erin, over her uterus, ovaries and uterine tubes
4. Holly, over her left neck and shoulder scars

Similarly, I added short pieces of red cord in a radial pattern to indicate treatment that was done with short-acting internal radioactive sources for:

1. Erin, who had Brachytherapy, which is radiation delivered by applicators temporarily inserted into her cervix and uterus.
2. Loraine, whose thyroid gland was destroyed by Thyroid Ablation, which is delivered by a short-acting radioactive drink.

Taryn's artifact (see Figure 11) resulted from permanent skin damage from radiation treatment to her upper arm. Holly described experiencing a temporary painful skin and tissue reaction to irradiation of her neck and shoulder. Both women explained that they had difficulty communicating with their radiation oncology team to get timely and appropriate wound management.

The Third Treatment Modality: Chemotherapy

Chemotherapy kills cancer cells and can damage normal cells.¹⁴³ Side effects of chemotherapy may include nausea and vomiting, infection, fatigue, hair loss, mental confusion or brain-fog, hearing and vision changes, skin changes and nail effects, and peripheral neuropathy, a condition that can mean numbness and tingling in the fingers tips and toes, or a

¹⁴³ Canadian Cancer Society. <http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/chemotherapy-and-other-drug-therapies/chemotherapy/side-effects-of-chemotherapy/?region=on>

burning sensation. These effects are usually temporary, although Eva described some persistent peripheral neuropathy in her fingers. These side effects and their intensity vary with the drugs that are used and the dosage given. Many effects, such as nausea, vomiting, and fatigue, can be controlled by other medications. Infection, as experienced by Eva, can be life-threatening. Immunotherapies or biotherapies are used to stimulate the immune system.¹⁴⁴ Taryn experienced severe flu-like symptoms, extreme pain, fatigue, nausea and vomiting, and skin reactions. She was also left with some residual brain-fog or confusion.

Chemotherapeutic drugs are very toxic and can damage the lining of veins. Central lines (in the upper chest) and peripherally inserted central catheters (PICCs) (in the upper arm) are placed in the body to convey chemotherapeutic drugs directly into major blood vessels. To indicate the internal lines, I added thick red and gold cord that begins at the top of AVAtar's heart and travels:

1. towards her right upper chest where it exits her body for Taryn's central line.
2. to her left upper arm to exit above her elbow for Eva's and Erin's peripherally inserted central catheters (PICCs).

The small white rectangles that hold the lines in place on AVAtar's chest and her upper left arm are made of non-stick dressings. They represent the sterile covers that protect the exit points of the central line and the PICC's dual ports. These catheters are usually not visible to anyone who is not involved in taking care of them. The internal part of the line is not visible as it is buried within the body and the external part is usually kept covered by a special dressing for sterility and the person's clothing for modesty. I have made both parts of the catheters visible to remind readers of the impact of chemotherapy treatment. These lines are invasive and the

¹⁴⁴ Canadian Cancer Society. <http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/chemotherapy-and-other-drug-therapies/immunotherapy/?region=on>

catheters require regular care to prevent blockage and infection. Erica also had intravenous chemotherapy but she said that she was not offered either type of line/catheter.

Side effect of chemo 1. AVAtar does not have any hair to represent the women who had hair loss with chemotherapy: Taryn, Eva, Erin, and Erica. The grey netting across the top of AVAtar's head makes their cancer-related brain fog (chemo brain) visible (see Figure 23).



Figure 23. Photograph of AVAtar: The second and third treatment modalities and side effect of chemo 1.

Side effect of chemo 2. Short pieces of red cord at the end of each of AVAtar's fingers indicate the burning sensation of peripheral neuropathy that troubled Eva.

The short pieces of silver cord at the end of AVAtar's fingers and around the toes of each foot denote the cold, tingling or numbing sensation of peripheral neuropathy experienced by Taryn, Eva, Erin, and Erica (see Figure 24).



Figure 24. Photograph of AVAtar: Side effect of chemo 2.

Additional features. In addition to representations of their organs, surgery, radiation and chemotherapy, and side effects, the women directed me to add additional features to AVAtar:

1. A Broken Heart. AVAtar's heart has a tear or break in it. This is an invisible, emotional scar. Eva said that each scare of recurrence or a new cancer has a very heavy impact, "Because it breaks your heart" (November 29, 2016).
2. Clouds, Fear of Recurrence. The women carry the worry of recurrence of their cancers with them. This is also an invisible, emotional scar. In the upper right corner of the canvas, there is a white, grey and black cloud because Eva said, "There are different coloured clouds" (November 29, 2016). A silver cord lines the inside edge of the white cloud because Taryn said, "My cloud has a silver lining" (November 29, 2016). I added a second grey and black cloud because Erica said, "So now I've got two little black clouds" (December 1, 2016).
3. Family and Friends. Erica requested that family and friends be added to the canvas (December 1, 2016). Underneath the clouds in the upper right corner there are adult and child figures to represent the important role family and friends played in each woman's experience, for both physical, social and emotional support.
4. Sore mouth. Eva said that AVAtar's mouth should look as though she had oral mucositis, a painful, non-visible side effect of some chemotherapy drugs (November 29, 2016). The red netting over her oral cavity represents her sore and inflamed mouth.
5. Tattoo. Pieces of black lace applique on AVAtar's left forearm represent Holly's very visible tattoo, her act of celebration and hope. Holly said, "There is always hope for a cure" (December 5, 2016).

Medical professionals. Once all the women's requested elements were added, I added two small figures (in little white coats) to the right side of AVAtar to represent the healthcare professionals, both male and female, who featured in the women's stories, such as doctors,

nurses, psychologists, radiation therapists, social workers, and physiotherapists (see Figure 25).



Figure 25. Photograph of AVAtar: Endings.

I am the figure behind AVAtar, as Eva suggested, a helper, companion, and support. As a visual means of communicating experience, I believe that AVAtar, the collective body map has the potential to touch, move, or impact many observers emotionally, perhaps in the way it has touched me. Even after many years of healthcare experience, I felt the effect of each treatment and side effect on these women strongly as I drew, traced, snipped, and stitched. My final addition to the helper's figure is a representation of what it felt like to grasp Erin's anger with my hand (see Figure 17).

What does AVAtar say to us? To a doctor or other healthcare professional, AVAtar might look like a crudely constructed technical map of internal organs, treatment modalities, and side effects. Yet, I hope that the symbols of the women's emotional stress (a scarred or broken heart) and the fear of recurrence (the black clouds), as well as cognitive difficulties such as brain-fog (the grey netting) stand out for the reader/audience, in addition to the more obvious physical effects depicted. A woman with cancer might pick out the symbols of treatment and side effect features that resonate with her own experience. She might also connect with AVAtar's lack of voice (loss of control), her blindness (uncertainty) about the future, perhaps even her difficulty hearing, understanding, and remembering all the information (brain-fog) she received, or her ever-present fear of recurrence (black clouds). A cancer educator might see a life-sized opportunity to teach women about the treatment and side effects of cancer. An artist might focus on the colours, shapes, and textures of the internal organs and the materials used to depict cancer treatment and side effects in a mixed media work. A person who does not have any knowledge or experience of cancer, or any medical knowledge at all, might need more guidance to interpret her symbols to hear and understand what AVAtar is trying to say. I see AVAtar as a figure in

motion, empowered and seeking action. She is not alone on her quest for action. There are people, such as family, friends and healthcare professionals, around her.

Found Poetry

Butler-Kisber (2010) describes *found poetry* as “the rearrangement of words, phrases and sometimes whole passages that are taken from other sources and reframed as poetry by changes in spacing and/or lines (and consequently meaning)” (p. 84). The *found* poem below is constructed from phrases the women used (their metaphors) that were predominant themes in each woman’s narrative and artifacts. Their phrases are italicized and bolded, and I added words and punctuation to connect the ideas. The poem speaks to the difficulties of diagnosis, fear of recurrence, uncertainties of living with cancer and the importance of hope. The pronoun “she” in the title could represent a mother, a daughter, a trusted friend or any figure of support.

Found Poem: She is my Saviour

Yes, there are ***Two little black clouds,***
Because it breaks your heart.
 But, ***There is life after cancer*** with
A silver lining since
There’s always hope for a cure.

S. Boyko, June 2017

I listened to the women’s voices, gathered their stories and carried the feelings that their stories evoked around with me day and night. To process my inner turmoil, a storm of sadness, guilt, and wonder, I dreamed of their stories, drew pictures, and wrote about them. I described in words and displayed what I understand of the women’s experiences (and their impact on me) visually in this arts-informed dissertation. I am prepared to answer my original research question: How do illness narratives and arts-based artifacts deepen our understanding of the cognitive and emotional needs of a cohort of adult women with cancer? Illness narratives and arts-based

artifacts deepened my understanding of the cognitive and emotional needs of a cohort of adult women with cancer by helping me *feel* their fear, anger, pain, frustration, and hopelessness, as well as their relief, joy, and elation. These arts-based ways helped me access their emotion and experience in ways that transcended the information that is available in quantitative patient satisfaction surveys and much of the quantitative literature. Through their narratives and personal artifacts, the women emphasized not only their physical ordeals but also diagnosis shock, fear of recurrence, and anxiety regarding how their disease would impact on their families and friends emotionally. These emotional needs were often not recognized or addressed in a timely way within the relationships they had with their healthcare team. As adult learners, the women demonstrated a variety of different styles for learning and communicating with their doctors as they searched for information to resolve their health crises and take action. Women who were convergers or assimilators in the way that they learned, and assertive in their communication styles, styles that were like those of most doctors, were more likely to acquire the information and support they needed, when they needed it. Women who were divergers or accommodators in their learning style and passive in their communication style had more difficulty finding information and support and sometimes had to find it outside of their treatment team.

Inspired by the potential of qualitative inquiry, I utilized arts-based methods and immersed myself in arts-informed narratives to discover a fourth dimension of the women's experience, the fleeting nature of *time*. The women often feared that the time they had left to live was running out. In contrast with the objective three-dimensional universe, I identify three dimensions of their subjective experience as: height of *presence* (personal influence), width of *scope* (individual responsibility), and depth of *feeling*. I did not ask whether the women were anxious, worried, or fearful, like quantitative satisfaction surveys. I heard the women describe

how their anxiety consumed every facet of their lives when they entered a cancer limbo-land, their lives disrupted. I did not ask if the women had physical or mental pain. I empathized with their descriptions of the gut-and-bone-and soul-wrenching pain that sometimes went unresolved. I did not ask if the women felt uncertainty about the future. I descended with them into a seemingly unending darkness when they described how they felt an absence of hope. They shared what it is like to lose control of their lives, to become invisible, blind to the future, and rendered mute like AVAtar. It was in their tone of voice, the words they chose, their body postures, and their facial expressions.

I grasped the women's strong sense of running out of time, the fourth dimension, as reflected in the things they feared would be left unsaid and undone in their lives if they did not survive their cancers. Their fear that they might not have made a difference to others, that their lives would not have mattered or that they would be forgotten strongly resonated with me. The women's narratives and personal artifacts also describe their determination, strength, and self-empowerment, infusing their stories with hope. The women and their narratives gave me hope.

In addition to the women's narratives, personal artifacts and my drawings and poems, AVAtar steps off her canvas to embody their physical and psychological experience in a compelling way. She makes what has been invisible, visible by giving wordless thoughts a form. The women are no longer silent since they have shared their stories. Does AVAtar appeal to your curiosity and grab your attention? "Look at me," she says. Can you see and hear AVAtar and all that she represents? What does she say to you?

CHAPTER SIX: INTERPRETATIONS AND CONCLUSIONS

- AVAtar: What did you learn from our stories?
- Researcher: Cancer makes deep emotional and physical scars that many people do not see.
- AVAtar: Can they see and hear us now?
- Researcher: I wrote about your stories, drew pictures and wrote poems to help them see and hear you.
- AVAtar: Will they care about our stories?
- Researcher: When they see you and hear your stories, they will.
- AVAtar, (see p. 142, para. 2).

This chapter presents me with an opportunity to look back through the “rear window” to summarize what I found in the adult education and healthcare literature regarding the cognitive and emotional needs of adults with cancer, as well as the findings of this qualitative research study. It is also an occasion to look forward through the “windshield” to suggest practical directions for continuing medical education and cancer patient education that has the potential to be transformational for doctors, other healthcare professionals and adults with cancer. Taking one last glance in my rear-view mirror, I will make sense of my life’s work and the path I have taken, to conclude with suggestions for future research.

Looking Through the Rear Window: Connecting Previous Research to Findings

Six brave women stepped forward to participate in this qualitative research study. When they learned that they had cancer, the women were faced with a sudden need to learn about their disease and treatment, and consider their own mortality. Their fear of the unknown and anxiety about the future strongly motivated them to learn new information from strangers who held the

knowledge and power to change their lives. The women encountered medical terminology that they did not always understand, while traversing unfamiliar places they would not normally decide to visit. The disorientation of diagnosis, medical language and environment created conditions that were not optimal for adult learning. They needed time to reflect on the new information they were gathering to reframe how they understood their world, so that they could solve their immediate problems and make important decisions about their lives. However, depending on the urgency of their health situations, sometimes the women did not have the opportunity to reflect, reframe and ask questions before they needed to make critical decisions about their health.

When interacting with their doctors and other healthcare professionals the women utilized a range of communication styles (passive to assertive), and different ways of making sense of the new information they gathered (assimilating, converging, accommodating, or diverging). The women also described having varying degrees of satisfaction when interacting with their doctors, whose styles of communicating and sharing information might have been different than their own. Their illness stories and personal artifacts revealed their resilience and determination, and their ability to transcend adversity and advocate for others. The disorienting dilemma that a cancer diagnosis creates triggered an intense need to learn that resulted in transformation of their perspectives and behaviours in different ways. These findings present cancer educators with an opportunity to better prepare both adults with cancer and their doctors to maximize the opportunity for learning that the disorientation of cancer presents. I intend to explore the legacy of the women's stories for reimagining adult cancer education in this chapter.

Examining the illness narratives and arts-based artifacts of a group of adult women with cancer has deepened what is known and understood about their cognitive and emotional needs.

The findings described in Chapter 5 suggest opportunities for changes to current adult education practice that could influence doctor–patient interactions, cancer patient experience and patient education. Perhaps by implementing these changes, cancer patients’ participation in decision-making and their satisfaction with the care they receive could improve. These findings also support and encourage thinking about how qualitative arts-based methods could be used for transformational learning and cancer education research. The women’s emotional, cognitive, and relationship needs, the conditions needed for transformational learning to occur and the merits of using arts-informed methods in inquiry will be summarized and discussed in this chapter from the perspective of the whole person.

Emotional, Cognitive, and Relationship Needs

While the women’s narratives expressed similar themes to those addressed in the literature, they placed more emphasis on the emotional impact of cancer. The women described considerable shock when they heard their cancer diagnosis and anxiety when waiting for referrals for more tests, specialist appointments, and treatment. They were uneasy about losing control over their lives, and lived with the fear that their cancer would recur, they would be diagnosed with a new cancer or both. The women felt a need to appear strong for their family and friends, sometimes placing the physical and emotional needs of others before their own needs. There were many instances in the narratives when the women’s emotional needs were not acknowledged by their healthcare team and they did not know where to find other sources of support. Perhaps these emotional needs were neglected because their objectively oriented doctors believed that dealing with emotion is the role of other professionals, they lacked the skill and sensitivity to recognize and assess distress in others, or they perceived the woman’s physical illness as requiring more immediate attention. The reasons for instances of this neglect are not readily apparent in the women’s stories.

Emotional support was needed at significant transition points in their illness. Becoming a cancer patient, starting treatment, and learning how to live with cancer and the fear of recurrence can generate significant anxiety. It became apparent that supportive information was not always available or timed to address these transition points. Information about their disease, treatment and how to manage their side effects not only facilitated healing, it greatly helped them to manage their anxiety. They also needed support services for their physical and financial needs, timely action regarding tests, results and treatment, and reassurance (hope).

The women's personal artifacts enhanced what is known in the literature and revealed in their narratives/ by providing the reader/audience with a sense of what it looks, sounds, and feels like to live with cancer. The shock, anxiety, uncertainty, stress, and fear generated by cancer are no longer static words on a page. These feelings walked hand in hand with the women throughout their narratives and some persist as they continue along their cancer journey. Aside from the physical side effects of cancer and treatment the women live with daily, their fear of recurrence persists.

With respect to their cognitive needs, as Back (2006) suggests, the women preferred to receive their information directly from their doctors. Doctors who were described as meeting the women's needs may have been more aware of their role as information providers, and more skilled at assessing and meeting their emotional needs, as well as forming relationships. They also managed to perform these roles within the standard amount of time that is allotted for patient interactions. How much did having a similar learning style to that of their doctor matter? The women who had similar learning styles to those of their doctors described having more satisfaction with the information they received with their doctors during their illnesses. Epstein and Street (2007) describe most doctors as assertive in their communication style and the

women's stories about their doctors affirms this statement. As Hovey et al. (2012) suggests, the transmissive teaching style was used most often when doctors provided the women with new information. Regardless of the gender of the doctor, when an assertive (or aggressive) doctor was paired with a woman who was passive in her communication style, the teaching style was mostly transmissive. When an assertive doctor was paired with a woman who was assertive in her communication style, the teaching style was more likely to be transactive. The learning and communication styles of doctors and patients, and the teaching style of the doctor did play a role in the women's perception of their relationships with their doctors, and their overall experience of care. Both healthcare professionals and adults with cancer might benefit from a greater understanding of how their preferences for learning and communicating influence their interpersonal relationships.

Other forms of generic information support, in the form of the information binder, and group teaching sessions led by nurses and radiation therapists provided minimal opportunities for dialogue and reflection. Both ways of providing secondary general information were transmissive and did not encourage transformational learning. These generic ways of conveying information to adults with cancer might be reviewed and enhanced to better meet their learning needs. To find the information and emotional support they needed, three of the women joined a peer-led support group like Grande et al. (2006) described, and two of the women turned to virtual peers on pertinent disease-related Internet forums.

What was more apparent in the women's narratives than in the literature was the importance and influence of their relationship with their doctors. All women experienced the disorienting dilemma of cancer but their ability to critically reflect, engage in rational dialogue and develop a new perspective on their illnesses was hampered when they did not have a

supportive relationship with their doctor and their emotional needs remained unmet. As the women learned experientially, by observing and reflecting on doing, even those who tended to approach interactions with their healthcare professionals passively, gained the confidence to ask their doctors more questions to participate in their care. This chapter will suggest ways that cancer educators can use this enhanced knowledge of the women's emotional, cognitive and relationship needs to help adults with cancer learn about their disease and treatment and cope emotionally.

Conditions for Transformational Learning

Did the women's cancer experiences lead to transformative learning? Transformational learning requires perspective transformation. Mezirow (1997) states that perspective transformation requires an environment where the individual participants: (a) had full information, (b) were free from coercion, (c) had equal opportunity to assume various roles (expert vs. novice) in the relationship, (d) both the learner and teacher can reflect on assumptions, (e) both the learner and teacher are empathetic and good listeners, and (f) both are willing to search for common ground. According to the women's stories, these conditions for perspective transformation were not always met through their learning environment and interactions with healthcare professionals.

English and Irving (2012) challenge Mezirow's perspective of adult learning as an individualistic activity by pointing out how important collaboration is to women's learning; they describe women as "connected knowers" (p. 248) and emphasize the importance of relationships to women's transformative experiences. The opportunity to "share their life narratives" is essential to women's "transformative experience" (p. 250). They also emphasize that relationships and mentors become more essential for women's transformative learning in times

of crisis. Their assertion that collaboration and relationships are necessary for women's transformation is supported by the women's experience stories.

In Appendix J, Conditions for Learning for Women with Cancer, I added elements of the women's experience to Mezirow's description of the *ideal* learning environment for perspective transformation. Based on their stories, I suggest that to create transformational learning, the women needed information about their cancer and treatment when they were ready and needed to receive it, and in ways that met their preferred learning styles. The women needed to feel welcome to ask questions and make decisions to the degree that they wanted. Both doctors and women needed to learn something new in the encounter; the doctors learned about the women's illness, beliefs and preferences, while the women learned about their cancer, treatment options and the support services available to them. The women expected appropriate treatment and hope; the doctors expected to facilitate treatment of the women's cancer and support services. The women expected to form a relationship with their doctors based on mutual respect. For this relationship to develop, dialogue needed to occur between doctors and women with cancer. When there was a difference in expectations, doctors and women needed to negotiate the type of treatment she would receive and the timing of treatment delivery and support. Suggestions for how these conditions might be created will be made in the section, "Looking Through the Windshield: Moving Forward" later in this chapter.

The key to meeting emotional and cognitive needs like those expressed by these women is to encourage more responsive relationships between doctor and patient based on mutual respect, empathy, and compassion, and grounded on open, dialogic communication through education. While many doctors and patients have positive and supportive relationships, most doctors are not aware of how the individual learning and communication styles of both the

doctor and the patient influences the patient's experience, or that patients expect their doctors to play a role in facilitating emotional support and providing hope. Most adults with cancer are forced to make a life-altering journey without the knowledge or skills to participate fully in their own care. With timely information made available in ways they can best absorb it, and access to emotional support when they need it, adults with cancer might learn to manage and make decisions about their cancer and treatment to the degree that they wish, instead of perhaps feeling subjected to an experience directed by others, as some of the women described. Information, reflection, and dialogue are the essential elements required for learning to be transformational. The results of this study present cancer educators with an opportunity to consider how continuing medical education for doctors might increase awareness and understanding of their role in providing information and emotional support, and how learning and communication styles can be identified and utilized.

Merits of Arts-Informed Inquiry

What did using arts-based methods bring to this inquiry? Their women's illness narratives and the stories they told of the meaning of their personal artifacts were filled with their emotional experience of cancer, reflections and insights. Hearing the emotions in their voices and seeing their reactions emphasized in their facial expressions and body postures conveyed what they felt and helped me to *feel* what their experience of cancer was like. As de Mello (2007) first suggested, the stories and artifacts did create the conditions for me "to live an aesthetic" or emotional experience (pp. 214-215). Constructing individual narratives about their illness experiences focused my attention on what they said, and highlighted what they felt. My artifacts—the poems, drawings, and reflections—enriched my interpretation of their narratives and personal artifacts by connecting with my empathy and unearthing my feelings and regrets.

Their illness narratives and personal artifacts deepened my understanding of the women's experience by:

- Making their physical and emotional pain evident
- Illuminating what is invisible or silent
- Forcing me not to look away
- Engaging my emotions
- Encouraging my self-reflection
- Heightening my awareness about what was missing from their experience
- Forcing new questions to the surface
- Involving multiple modes of representation

It is my hope that their stories will have the same effect on others who read, hear and see them. If the women's illness stories do cause an emotional response in others, such as doctors and other healthcare professionals, perhaps this emotional disorientation will encourage reflection and receptivity to learning new concepts and putting them into practice.

Resonant arts-based themes. In addition to their emotional, cognitive, and relationship needs, the illness narratives also revealed themes through the women's own metaphors: (a) Two Little Black Clouds (fear of recurrence), (b) Because it Breaks your Heart (protecting others), (c) She is my Saviour (importance of helpers), (d) There is Life after Cancer (surviving), (e) Silver Lining (finding unexpected benefit), and (f) There is always Hope for a Cure (never losing hope). These metaphors were highlighted in the Found Poem, "She is my Saviour" on p. 154. By examining the women's personal artifacts and their meanings, I emphasized what the women felt: the fleetness of time (metronome), need to fight and be strong (dragon), need for a saviour/helper (dependence), transcendence (scar), celebration (tattoo), and empowerment (of

self and others). The “Joyous Spirit” and “She is my Saviour” poems and the “Cancer Dragon” and “Hope Flowers” haiku further explored these meanings.

AVAtar, the collective body-map draws together and displays their themes of experience wholistically through a variety of symbols: the women’s altered sense of self (blindness, muteness, deafness, and baldness), their endurance of invasive medical procedures (biopsies, surgeries, PICC, and Central lines), physical scars (black thread, red netting), mental scars such as their fear of recurrence (clouds), worry/trauma (broken heart), and their cognitive difficulties (brain-fog). She also represents their resilience in the processes of reclaiming identity (creating a visual presence), healing and empowerment (figure in motion), and the role of helpers in the background (family, friends, healthcare professionals, and the researcher). AVAtar is a powerful visual presence.

By gathering, distilling, and reflecting on the stories of six women with cancer in their individual narratives, I appreciated instances where the physical, emotional, practical, spiritual, and cognitive needs of women with cancer were not met. I also described instances where women developed relationships with their doctors and felt engaged and empowered in their own care. Their personal artifacts highlighted their pain, trials, and triumphs. Through AVAtar, I reinforced and presented the women’s physical, emotional, and cognitive needs, as well as their empowerment, visually. Using arts-informed inquiry not only provided a means to deepen what is known about the experience of a group of adult women with cancer, it also provided a platform from which to reimagine how this knowledge could be used to improve care.

Looking Through the Windshield: Moving Forward

As demonstrated in the literature and highlighted by the women’s illness stories, the current healthcare system has been designed to objectively focus on treating the individual’s

disease rather than the whole person with cancer. Traditionally, less emphasis has been placed on recognizing and supporting cancer patients' psychological and social needs. Since governments must be fiscally responsible and healthcare budgets are not likely to increase (Ferguson, 2017), recommendations based on the results of this study should be practical and feasible, to increase the likelihood that they might be implemented. They should also focus on the design and provision of education for physicians, oncologists, other healthcare professionals and adults with cancer. The recommendations are shaped by my knowledge of how people with cancer are treated, the structure of the Canadian healthcare system, especially in Ontario, and how Ontario cancer centres function. Topics arising from this research study, such as differing learning and communication styles and role expectations, the importance of narratively competent doctor–patient relationships, utilizing continuing medical education, and suggestions for changes in current education process will be reviewed and addressed.

Matching Communication Styles and Role Expectations

The communication styles and role expectations of doctors and women with cancer in the therapeutic relationship are very important, but often not compatible. This became very clear through the women's stories. While these factors are known in the literature, in combination these factors can have a much more powerful effect, sometimes causing additional anxiety and despair. What is not evident in the narratives to the reader/audience, but is known to me as the researcher, is that some of the women have doctors in common in their stories. The doctors are referred to only by a letter of the alphabet and they are assigned a different letter in each of the women's narratives. In the first instance, three of the women had the same doctor. One of the three women described her relationship with him very negatively. In their own stories, the two other women agreed that his behaviours were not as conducive to a supportive relationship as

they experienced with other doctors. However, they both stated that they got what they needed in terms of care from him. In the other instance, two of the women have another doctor in their stories in common. One of the women found him to be extremely supportive and empathetic. The other woman found him to be patronizing and resistant to her participation in her own care. The communication styles and role expectations of both doctors and patients greatly impact the patient's experience.

Could the doctor and patient be matched by their communication style and role expectations? Coffield, Mosely, Hall, and Ecclestone (2004) remarked that there is not enough evidence to support matching learning style with corresponding teaching style to benefit adult learners. They emphasize that learning is complex and influenced by many factors, such as gender and subject matter. I surmise that in situations where adults with cancer are the learners, their emotional needs add even more complexity to learning. The Canadian publicly funded healthcare system matches oncologists and patients based on the type of cancer the patient has, the specialized knowledge of the oncologist and his or her availability at the cancer centre closest to where the patient lives. Like care for any other disease or ailment, the cancer care system is disease-centred rather than person-centred. Oncologists spend 14-16 years training to become oncology specialists to provide treatment that is based on the most recent scientific evidence. Shortages of oncologists in certain jurisdictions would make matching doctors and patients based on learning and communication styles challenging. Instead, having an institutional policy in place that allows a patient to switch oncologists within the same facility if they are personally incompatible with their oncologists, as Eva did, is a reasonable option. There is variation in how this request is handled in each cancer centre or hospital, but these processes and their outcomes are considered confidential to protect the privacy of the patient and the doctor. However, in a

2015 Ontario hospital survey, 96 of Ontario's 149 public hospitals (64%) reported having processes for complaints resolution in place (Health Quality Ontario, 2015). Although patients and families should always be informed of these support options, as Erin's story attests, many people do not know how to make a formal complaint or to access the services of the patient relations department. Practically, the availability of oncologists that specialize in treating certain types of cancer will limit whether a request to change doctors can be accommodated. However, offering appropriate continuing medical education that elicits an emotional response and perspective transformation might increase doctors' awareness of the importance of communication styles, role expectations and relationships to cancer patient experience, encourage changes in their communication and teaching behaviours and increase patient satisfaction with care. Perhaps arts-based tools such as AVAtar could be used to create emotional responses to patient experience stories during continuing medical education presentations and workshops that might trigger transformational learning and behaviour change.

Building Narratively Competent Relationships

The relationship between the doctor and the woman with cancer is the essential foundation of her experience. Judging by the volume of research that looks at the provision of information and communication in medicine, cancer patient coping skills and improving patient satisfaction, as featured in the review of the literature in Chapter 2, I believe that current healthcare practice has minimized the importance of developing doctor–patient relationships. The women expected and needed to form a connection with their doctors for their information and emotional support needs, and that relationship varied between being one of dependence or a partnership.

Education for doctors regarding the importance of the doctor–patient relationship to meeting their patients' cognitive and emotional needs, developing narrative competence and

supporting the patient's transformational learning could fill this gap in practice. In addition to reviewing the clinical evidence that supports the importance of the doctor–patient relationship, this education could include practicing active listening skills by learning to listen to patient stories without interrupting, anticipating the story's conclusion or immediate judgement. Working with standardized patients (specially trained actors) during workshops could help doctors practice listening, valuing, and acting on patient stories during the clinical interview to become more narratively competent. Storytelling can create an environment that supports formation of the relationship between doctor and patient. Being listened to, having the opportunity to ask questions and his or her concerns acknowledged are central to forming this relationship.

By asking questions and prompting patients to share more information during clinical encounters, doctors can coach patients to tell their stories within the safety of the therapeutic relationship. I did develop a trusting relationship with my participants, even those I met for the first time by being open about my perspectives, transparent in my methods, non-judgemental and very patient. I encouraged storytelling by prompting, reassuring, and gently questioning. I knew we had entered a trusting story-telling relationship when the participant relaxed and let her story flow, when she expressed anger or sadness openly, when she used profanity easily, or when she shared very personal details about her life and wellbeing with me that went beyond the Interview Guide. By inviting, gathering, valuing, and acting on the women's illness stories, I demonstrated my understanding of narrative competence.

Employing Existing Continuing Medical Education Pathways

The study by Jones et al. (2011) discussed in Chapter 2 did emphasize teaching doctors and other healthcare professionals to recognize the learning and communication styles of

patients. The program was innovative in its use of standardized patients (specially trained actors) and participants evaluated it as effective in conveying the importance of learning and communication styles and how to identify these in practice. Participants demonstrated greater awareness of their own learning and communication styles as well as those of the standardized patients they practiced with. The course required 4 hours of each clinician's time, a trained facilitator, and four standardized patients. The study results indicated that only one doctor attended the program because of the time commitment required. As a former instructor for this program, I can attest to the program's benefit to the individual clinician's confidence in his or her communication skill. Unfortunately, the administrators of many cancer centres in Ontario judged it to be too expensive in terms of the cost of each healthcare professional's time and the additional resources necessary to sustain it. The program was later adapted for the online learning environment without the interactive role-playing component with standardized patients (de Souza Institute, 2017). The individual professional now pays for the 10-hour course and completes it on their own time. Although suitable for all healthcare professionals, particularly oncology nurses, currently the course has not been accredited to provide continuing medical education (CME) credits for physicians and specialists and requires even more of the clinician's time than before. Modification of course content and application for CME accreditation could make this course a viable and accessible education option for doctors and other healthcare professionals.

As stated earlier in Chapter 2, both the Royal College of Physicians and Surgeons of Canada (RCPSC) and The College of Family Physicians of Canada (CFPC) specify the role of "Communicator" as a required competency for both undergraduate and continuing medical education for physicians and surgeons who maintain membership in these colleges. Cancer

educators could build on this core competency by designing continuing medical education sessions that include content on adult learning principles and how adults learn when they have cancer, as well as provide training on communication skills, relationship building, and narrative competency. The sessions could meet the standards of the Royal College of Physicians and Surgeons of Canada (2017) and The College of Family Physicians of Canada (2016) so that physician participants receive CME credit hours on completion. However, since not all surgeons, oncologists and family doctors retain membership in their respective Colleges after graduation, CME credits may not be enough of an incentive for all doctors to participate. As objective, behaviourist and liberal thinkers, many oncologists prioritize education that updates their knowledge on the latest scientific research and guidelines for cancer treatment. In Ontario, oncologists may be providing services to cancer centres as independent contractors, which may limit the ability of hospital administrators to make training that impacts on professional practice mandatory. However, doctors' interest in attending an adult learning/relationship building CME session might be stimulated if an arts-based "disorienting dilemma" was introduced first at interdisciplinary educational rounds in each cancer centre. Perhaps an adult cancer patient who has been trained in storytelling could tell his or her story, or AVAtar could tell her collective story via recorded presentation.

To encourage doctors' participation in CME sessions it is also important for cancer educators to think like doctors and design education that meets their converger/assimilator learning and assertive communication styles, and fits into their busy schedules. Sessions could be (a) delivered by a doctor or an education professional who is accepted as a peer, (b) offered in one-hour sessions at cancer centres and hospitals before the start of clinic hours or at lunch, and (c) offered in longer, hands-on workshops at medical conferences. The information should be (a) concise, (b) present clinical evidence (both quantitative and qualitative) that supports why

doctors need to understand and recognize learning and communication styles and the importance of building relationships, and (c) use arts-based features such as video clips of patient stories or other arts-based modalities such as poetry, patient and doctor artwork, or body-maps to enhance and humanize the content, encourage reflection, and discussion. When enough time and standardized patients (specially trained actors) are available, role-playing practice sessions could be included. For those adult learners who may prefer to access online and asynchronous learning when he or she has time available, perhaps the aforementioned *Patient Teaching and Education* online course (de Souza Institute, 2017) which does not include content on the importance of relationship building or emphasize the role the doctor plays as a patient educator, could be modified and accredited to include these topics and arts-based features in future.

Traditionally, continuing medical education sessions have been primarily transmissive in delivery. How can the adult learner's own emotions be accessed so that continuing medical education can be more transformative? Arts-based activities introduced at medical education conferences, when doctors have time set aside for learning, opportunities to learn from, and with peers and earn CME credit hours could normalize thinking and talking about "feeling." Activities could include reflective writing, poetry writing, music therapy, art-making and drama to provide the conditions to create a "disorienting dilemma" for doctors as their catalyst for a change in perspective, attitude and behaviour. Perhaps doctors could "interview" AVAtar (in the form of a specially trained actor) to hear what she has to say about her emotional and cognitive needs. The transformative impact of any of these arts-based activities could be explored in future arts-informed narrative research with doctors.

Practical Suggestions for Transformative Process Change

In addition to promoting continuing medical education for doctors and other healthcare professionals, I provide some practical suggestions for changes in clinical practice that are based

on the women's experience:

Implement a conversation guide. A simple tool could be used to facilitate and expand the consultation conversation between doctors and patients. A “cancer needs dialogue tool” is a short list of questions that doctors and nurses could ask patients about their cognitive and emotional needs and expectations at the first consultation visit. The list I created is based on the “Ask-Tell-Ask” communication dialogue of the American Medical Association (2015): *Ask* the patient what they already know about their illness and what more they want to know, *Tell* them what they want to know, and *Ask* them to summarize what you just told them and *Ask* what else they want to know that may already be in use. Additional questions regarding what the patient wants to know, how they like to learn and what their emotional needs are, that were derived from the women's stories, have been added to this list. This short list of suggested questions to ask women with cancer that is based on the women's illness narratives and the AMA dialogue is available in Appendix K, Cancer Needs Dialogue. This list builds on and maximizes the existing culture and structure of the formal clinical consultation. Since the literature shows that eliciting the patient's narrative may only take an additional 2 minutes of consultation time (Langewitz, et al., 2002), this short, guided conversation regarding the patient's cognitive and emotional needs aligns with current clinical practice and might not adversely affect the very tight schedules in busy cancer clinics. It may more quickly and clearly elicit the patient's cognitive and emotional needs than current practice. The usefulness of this tool could be explored in future research with doctors and patients.

Normalize emotional support. Ask about and assess the patient's need for emotional support at the time of the first clinical encounter. Taryn suggested making the psychological support person part of the adult's care team right from the first oncology visit to normalize the

need for emotional and social support. “Patients need to know who their healthcare team is, what their jobs are, what their expertise really is. When you are in to be diagnosed it shouldn’t just be a doctor and a nurse, there should be a supportive care person there.”¹⁴⁵ This suggestion might be difficult to implement in most cancer centres because of the availability and workloads of supportive care staff (such as psychologists and social workers), however after learning more about how important emotional support is to adults with cancer healthcare professionals may be motivated to find new ways to ensure patients know how to find support for their emotional needs when they need it most. Taryn’s message emphasizes that an adult’s need for emotional support during illness should be *normalized*. Societies’ expectation that cancer patients must always be strong and fight their disease can create the perception that an individual may appear to be weak if they seek psychological help with coping with their illness.

Facilitate access to more customized information. Patients should have access to information that is specific to their cancer, the questions they have about their treatment and their age. Healthcare and cancer education professionals can help them find it. Holly would have liked more information about her cancer, a chance to ask questions and to know that peer groups for adolescents and young adults existed. Erin wanted additional information specific to her cancer but could not find a source she felt she could trust. In addition to information from their doctors and other healthcare professionals, hospital librarians and cancer educators can recommend books, websites and other sources of information to patients and families. This is a relatively low-cost solution in hospitals and cancer centres where libraries already exist. People with cancer need to know when there are information resource people available and how to find them. Eva did not know there was a patient library in her cancer centre until she was diagnosed with her third cancer.

¹⁴⁵ Taryn transcript, p. 30, lines 38-40

Make group learning more accessible. By providing basic information to many people at once, group information sessions maximize the cancer educators' time and resources.

However, as Erin expressed, and Savage, Arif, Smoke, and Farrell (2017) attest based on their survey of cancer patient learning preferences, some people do not like to learn in groups and prefer face-to-face teaching when they are ready to learn. In addition to allocating time for questions and answers during group learning sessions, make additional time available for patients to ask their questions privately after the session if they wish. Information sessions could be recorded and available on demand on cancer centre websites or in DVD format in patient libraries. Since cellular telephones and other digital devices easily record video and audio, this would be a low-cost option to implement. Cancer patients could choose the best time to review the topics that interest them, when they are ready to learn and when their support people are at home to learn with them. In addition to expressing her dislike for group learning situations, Erin found that they were offered too late to be of use for her.

Make group learning responsive to patient needs. By asking patients what they need to know, group information sessions could be tailored to provide specific information for some of the more common types of cancers, in addition to only offering generic sessions on the nature of cancer and various treatment modalities. The sessions could include instruction on how to find additional, accurate, and current cancer information online, such as reputable cancer organization websites, and online disease-specific cancer patient forums and how to assess the safety of these sites. Increasingly, adults with cancer are turning to the Internet for information about cancer and its treatment. Taryn and Erica navigated the Internet skillfully. Eva, Erin, and Holly tried to find information about their cancers at different times during their illnesses but did not know where to

look for the information they needed or what information they should trust. The group sessions should also mention any local peer support groups and how to contact these groups.

Give patients a choice. Which organizations and Internet sites provide reliable and accurate information about cancer, treatment, and living with cancer? Hospital librarians and cancer educators could provide regularly updated lists of reputable and accurate sources of information about cancer, treatment and managing side effects, and the emotional and social supports available for patients and families who would like more written information. For example, the Canadian Cancer Society and the National Cancer Institute are considered by most cancer educators to be reputable sources of information (Cancer Patient Education Network, 2017). Additionally, the Canadian Cancer Society employs cancer education specialists who answer patients' cancer questions by telephone and by email. They have a peer matching service that can match a new cancer patient with an experienced cancer patient to talk to based on their disease type, gender, and age. The resource lists could be offered to patients to supplement generic written information they receive such as the information binder that Eva and Erin mentioned, when they choose to find more information on their own. Resource lists could also be available on the institution's website for patients and family members to access when they are ready to look for more information.

Information and training. Include information about learning and communication styles in general group learning sessions to help patients identify how they like to learn best and seek out information they can use. Offer training for patients who would like to learn how to tell their illness story. The training should include: (a) learning to listen to stories by reviewing the recorded stories of other patients, (b) exploring the power of storytelling in group discussions,

and (c) reviewing the basic elements of story structure. Former patients could volunteer to coach patients as they learn to tell their stories.

Potential for Personal and Organizational Transformation

The women who volunteered to tell me their stories were women who wanted to help make changes to the care that people with cancer receive. Taryn and Erica came to their illnesses with confident voices. Eva and Holly found their voices through the process of experiential learning. Erin and Loraine joined a peer support group to find their voices and learned about self-advocacy from other empowered women.

The research process did facilitate a change in perspective or understanding for some of the women, and they described being more critically aware of the established healthcare system around them and their options for empowerment. For example, Erin is now aware of the role that the patient advocate plays in the hospital where she was treated for her cancer. “I didn’t know that there’s an advocate in the hospital that will speak for me when I’m feeling I can’t.”¹⁴⁶ Loraine stated that she feels ready to ask questions about the next steps in her care. “It [asking questions] would be a wise decision.”¹⁴⁷

Taryn, Eva, and Erica were empowered before they participated in the study. Erin felt relief at the telling and grateful for the opportunity to tell. “Oh, thank you so much. I really appreciated this because it’s difficult when you get there and I know you’ve had the background in it. So, you get what I’m saying.”¹⁴⁸ Loraine said that, “it was the best thing I’ve ever done.”¹⁴⁹ Holly is just getting started in her career as a healthcare professional and advocate for young adults with cancer. She is well educated, fully self-empowered and ready to speak for herself and others.

¹⁴⁶ Erin transcript, p. 37, lines 25-27

¹⁴⁷ Loraine transcript, p. 26, line 37

¹⁴⁸ Erin transcript, p. 36, lines 16-17

¹⁴⁹ Loraine transcript, p. 30, line 1

Because of my previous healthcare experience, I understand the challenges of trying to change the actions of established individual healthcare professionals like doctors (Drummond, Simpson, Sinclair & Walker, 2017). It is also difficult to change healthcare policy directly as an individual in hospital systems that the Institute of Medicine (2012) describes as complex, dynamic, and political. Even when the organization initiates change, processes may still change slowly in large organizations. Culture change, or the changes in values, beliefs, and actions of individuals who work in large healthcare organizations can come even slower.

However, after reflecting on the suggestions for creating transformational learning for adults with cancer (see Appendix J, Conditions for Transformational Learning for Women with Cancer), and seeing AVAtar, the collective body map (when these are presented and published), doctors, other healthcare professionals, and cancer educators may be influenced to reflect on their practice and change their actions individually or influence the change of hospital policies in some way. Based on my experience, and as illustrated by the literature and the women's stories, the current hierarchical power structures that are firmly entrenched within medical institutions are centred on doctors as the leader of the healthcare team. To promote perspective transformation and system change, transformational education for hospital administrators, doctors, and all members of the healthcare team would require introduction of a need to learn by presenting a dilemma or predicament to be resolved and encouragement of reflection and dialogue.

Patient voices and stories have the potential to change minds and attitudes. Patients can (a) be invited to tell their stories at doctors' educational rounds and meetings; (b) become faculty for the design and implementation of curriculum for communication, person-centred care, and narrative medicine courses and workshops; and (c) present their stories at medical and cancer

education conferences and in community forums. I also see the opportunity and the need in the literature to explore arts-based forms of research *with* doctors and patients working together to explore relationships, communication and transformative learning. This might take the form of designing, implementing, and evaluating new curriculum for communication training utilizing arts-informed and narrative ways, such as writing, drama, and music. I choose to assume the educator and researcher roles to affect change in medical culture. Narrative and arts-based methods can help create continuing medical education that begins with a disorienting dilemma, to set the stage for learning something new, fostering dialogic interaction and personal reflection.

Creating Narrative Safety

In Chapter 2, I described how narrative competence and narrative medicine can build empathetic relationships between doctors and patients that are beneficial to all. However, to promote and support developing narrative competence, “the capacity to recognize, absorb, metabolize, interpret, and be moved by stories of illness” (Charon, 2007, p. 1265), a climate of narrative humility is required. DasGupta (2008) describes narrative humility as accepting that our own story is not universal, and that we cannot completely understand another’s story. Humility requires self-evaluation and reflection. When we have achieved narrative competency (skill) with humility (attitude), I believe that we will have created what I describe as “narrative safety.” In the healthcare context, practices that are culturally unsafe are described as actions that “diminish, demean or disempower the cultural identity and well-being of an individual” (Brascoupé & Waters, 2009, p. 7). What is a narratively unsafe practice in healthcare?

A healthcare professional perpetuates a narratively unsafe practice when he or she (a) does not seek or discounts the experience or the voice of the ill person (and family members), (b) does not ask for or fails to respect the patient’s needs and wishes, and (c) does not provide an

environment of dialogue and reflection where the patient can realize transformational learning. A narratively safe practice would (a) encourage patients to tell their illness narrative (ask me what I know of my illness), (b) elicit and incorporate the patients' emotional and cognitive needs and their wishes for care (ask what matters to me), and (c) provide opportunities for patients to ask questions and engage in dialogue and reflection (ask what I understand and what more I need to know) within a series of clinical encounters. What structures, processes, and practices in healthcare create difficulties for patients to tell their stories?

The women identified practitioner and institutional barriers, such as the converger and assimilator learning styles that differed from their own learning styles, the patriarchal attitudes, and aggressive communication styles that some doctors displayed towards them, and limited opportunities to ask questions and share information. These barriers hampered obtaining illness narratives, creating dialogue, supporting reflection and perspective transformation. The cancer patient illness narratives shared with me revealed issues with women getting the information they needed from their doctors, in the way that best suited them and when they needed it to make decisions, manage their own care, and cope with the challenges of their illness.

Borrowing from the concept of cultural safety, I suggest that an environment of narrative safety would promote acknowledging, respecting, and empowering the personal identity and well-being of the individual. I propose that cancer educators and healthcare professionals consider a narrative continuum that consists of developing narrative awareness (awareness of our own story and that other's stories differ from our own), narrative sensitivity (awareness that our story influences how we understand other's stories), and narrative competence (being moved by other's stories of illness) with an attitude of narrative humility (self-reflection to foreground the patient's story) as essential for doctors and other healthcare professionals to create narrative safety.

With this continuum in mind, the next step would be to influence individual attitudes and eventually, system changes to facilitate the creation of narrative safety, in hospitals, clinics, and doctors' offices. This process would begin with education for healthcare professionals about the potential of narratives to create awareness of differences in our experience, sensitivity to how our own narratives affect how we hear the narratives of others, and competence where we learn to listen, value and act upon the stories of others. The essential background of narrative humility can only come from the introduction and encouragement of self-reflection activities for healthcare professionals and the consistent practice of reflection. A narratively safe place is an empathetic space where every person can tell their story.

Looking in My Rear-View Mirror: Researcher's Reflection

Hearing the women's stories, writing about their narratives, and the dissertation process forced me to examine my own values, purpose, and mortality by looking inward and looking backwards in time. I explored my feelings, conducted an internal inventory of my legacy, and reflected on my own actions as a healthcare professional and cancer educator. In the introduction of this dissertation I asked, "Did I do enough for patients, families and healthcare students?" No, not always. I can recall instances where I did not recognize or understand the depth of confusion, anguish or the existential crisis that cancer can cause patients and families. I did not see the superficial objectivity of healthcare practice and education. I did not encourage deeper reflection in my students.

I also asked, "What more can I do?" I can find ways to share patient stories and re-imagine how I present my research findings so that I can create the conditions for the reader/audience to also have an aesthetic experience. I can create disorienting dilemmas for others by my words and art in presentations and in education practice. I can create healthcare

professional, healthcare students, and cancer patient curriculum with patients who are the content experts. I can find ways to offer arts-based reflective activities, such as expressive writing, collage and body-mapping, to adults with cancer in the community. The women have shown me that there are exciting possibilities for empowering and transformative cancer education using arts-based methods in an increasingly connected online world to be explored.

How has this research changed me? What have I learned? As an experienced healthcare professional in the field of oncology, I will always view the world objectively. Approaching the interviews in my accustomed role of healthcare professional/administrator/teacher was easy. The reality was that listening as both an objective researcher and a fellow human being was hard. I felt mental anguish, frustration, anger, and guilt. Writing about their stories, once I learned to lower my protective shield and let myself feel the women's emotion, was even harder. My committee, especially my supervisor, pushed me to explore the subjective side of my nature, instead of wearing my comfortable, well-worn objective shoes while I analyzed my data, created my poems and drawings, and wrote this dissertation. There were times when I engaged in a monumental struggle between my literal and abstract selves, producing objective, mechanical text that did not do the women's illness narratives and personal artifacts justice. Fortunately, my committee (and I) persevered. I was responsive to their encouragement because my professional and personal lived experiences taught me to be receptive to the views and experiences of others. I needed their reassurance to jump off the metaphoric cliff.

The personal transformation wrought by the passing of time and my life experience enabled me to approach this research with an open heart and mind that helped me to hear the stories of women with cancer, as well as understand the context, processes, and education that helped to shape my colleagues' actions. My greatest learning, by far, has been the importance of

patiently listening, observing, and allowing myself to feel. These simple actions are the beginning of understanding what it means to be ill and how to help others. The women's experiences emphasized how important it is to see the whole person with cancer, not just the physical illness, and to build a relationship between the doctor and patient (and each other) by listening and engaging in good, dialogic communication. I learned that qualitative research and arts-based methods are powerful tools. I learned not to fear them and I will take them up again willingly.

Was I trustworthy? Did I meet the criteria for qualitative research that I specified in Chapter 3? By fulfilling my commitment to my participants, by being honest, dependable and representing their stories fairly and by employing member-checking, I believe I was. Was I authentic? The women trusted me enough to share their stories. They gained insight into their own experiences and expressed the benefit of telling their stories. Those who were not already empowered by their own experiences when they arrived for their interview, expressed knowledge of their own power as they left. Did I create the conditions for the readers/audience to feel the participants' stories? Only the reader/audience can answer this question. AVAtar asked me whether their stories would make a difference. I promised to do my best to make their stories heard, to make a difference in how adults with cancer receive care.

Did the women tell me what they thought I wanted to hear? Regardless of whether the women came to the interview thinking that they knew what I wanted to hear about their cancer experiences, there were both positive and negative elements in each woman's story. I believe that their engagement in the interview process, and their belief in the purpose of the research minimized the likelihood they felt coerced into participating. What about the experiences of other adults with cancer? Aside from their ages and socio-economic status, the women who

participated in this qualitative research were a relatively homogenous group of white, non-immigrant, and heterosexual women, like myself. I do not intend to make any generalizations based on their experiences, however I am curious to know if, or how the experience stories of non-heterosexual women, women of different ethnic backgrounds and cultures, women older than 65 years of age, immigrant women, or women who live in other locations may be different than those shared by my participants. It would be of great interest to me to hear the stories of other women and men as well, and to understand their experiences, commonalities and differences by initiating other research projects.

Areas for Future Research

In addition to exploring the impact of the women's stories on doctors, other healthcare professionals, healthcare students, cancer educators, and administrators, future areas of arts-informed narrative research with adults with cancer could include exploring the stories of other women with cancer who are from diverse cultural and ethnic backgrounds and lifestyles, the stories of men with cancer, the stories of young adults and older adults with cancer and the stories of surviving partners and family members. Other questions this research raises are: How has participating in an arts-informed narrative inquiry impacted on the lives of these adult women with cancer? What are the cognitive and emotional needs of oncologists? What could enhance their learning and make their relationships with patients and other professionals transformational and more satisfying? Exploration of the stories of doctors and other healthcare professionals could reveal a wealth of information about their emotional and cognitive needs. This information could help design continuing medical education that enhances both patient and healthcare professional experience as adult learners. In addition to the poetic, theatre, and arts-based methods previously mentioned in the literature review, other arts-based methods, such as

body-mapping, collage work, writing collective narratives, and poetic inquiry, could be used collaboratively with participants to explore the experiences of adults with cancer and their healthcare professionals.

In alignment with the qualitative literature that describes using illness narratives, this research study affirmed that there is much more to learn about the emotional and cognitive needs of adults with cancer by listening to their illness stories and examining their personal artifacts. Knowing what adults with cancer need, especially when the patient has difficulty putting these needs into words, could lead to many more practical recommendations for change in how cancer information and cancer care is provided. This study also adds to the literature that demonstrates how arts-based methods, such as poetry, artwork and body-maps, are effective ways to communicate the experience of illness to others. If, as Moore (1994) suggests, medicine was to treat the symptom as a symbol, as an artful *lens* through which to see the illness in a different context, what more could be learned about the person's whole experience? How could this lens impact on the art and science of medicine? Future work will involve exploring how the products of this research study can communicate the experience of adult women with cancer to doctors, other healthcare professionals and other adults with cancer. Looking at, and engaging with, the experience of adult women with cancer helped me to "reimagine our world and put that reimagining into effect for an improved future" (Garbutt, 2017, p. 280) in adult education and adult cancer patient care.

Last Words: Make It Better, not Worse

In closing, I introduce poet Elspeth Murray (2008), who speaks eloquently on the importance of clear, simply worded information and effective communication in the YouTube recording of her poem, "This is Bad Enough." Murray wrote this poem when she worked as a

writer for the South-East Scotland Cancer Network, in Edinburgh, UK. When she states, “Because this is bad and hard and tough enough so please speak like a human make it better not worse,” Murray asks healthcare professionals to speak clearly and simply to make the experience of cancer less clinical and more humanistic, by providing information and communicating in a way that meets their cognitive and emotional needs. The women’s illness experience stories resonate with her words.

This is Bad Enough

This is bad enough

So please ...

Don’t give me gobbledegook.

Don’t give me

pages and dense pages

and

“this leaflet aims to explain ...”

Don’t give me

really dodgy photocopying

and

“DO NOT REMOVE

FOR REFERENCE ONLY.”

Don’t give me

“drafted in collaboration with

a multidisciplinary stakeholder

partnership consultation

short-life project working group.”

I mean is this about

you guys

or me?

This is hard enough

So please:

Don't leave me

oddly none the wiser or

listening till my eyes are glazing over.

Don't leave me

wondering what on earth that was about,

feeling like it's rude to ask

or consenting to goodness knows what.

Don't leave me lost in another language

adrift in bad translation.

Don't leave me

chucking it in the bin

Don't leave me

leaving in the state I'm in.

Don't leave me

feeling even more clueless

than I did before any of this

happened.

This is tough enough

So please:

Make it relevant,

understandable –

or reasonably

readable at least.

Why not put in pictures

or sketches,

or something to

guide me through?

I mean how hard can it be

for the people

who are steeped in this stuff

to keep it up-to-date?

And you know what I'd appreciate?

A little time to take it in

a little time to show them at home

a little time to ask "What's that?"

a little time to talk on the phone.

So give us

the clarity, right from the start

the contacts, there at the end.

Give us the info

you know we need to know.
Show us the facts,
some figures
And don't forget our feelings.
Because this is bad
and hard
and tough enough
so please speak
like a human
make it better not worse¹⁵⁰

¹⁵⁰ Written for the launch of the cancer information reference group of SCAN, the South East Scotland Cancer Network 20th January 2006. © Elspeth Murray 2002-2011. www.elspethmurray.com
http://www.elspethmurray.com/Poems/poems_badenough.htm

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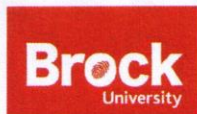
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Appendix A

Ethics Clearance Letter



Brock University
Research Ethics Office
Tel: 905-688-5550 ext. 3035
Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 5/20/2016
PRINCIPAL INVESTIGATOR: ABBEY, Sharon - Teacher Education
FILE: 15-278 - ABBEY
TYPE: Ph. D. STUDENT: Susan Boyko
SUPERVISOR: Sharon Abbey
TITLE: Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW

Expiry Date: 5/31/2017

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 5/20/2016 to 5/31/2017.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 5/31/2017. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Kimberly Maich, Chair
Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix B


Recruitment Brochure

Page 1

Have You been
Diagnosed and
Treated for Cancer in
the Sudbury Area?

I would like to hear about
your experience with cancer.
I am interested in learning
about the information and
education you received about
your diagnosis, cancer
treatment and living with
cancer after treatment.

Please tell me your story...




This research study has been
reviewed and received ethics
clearance through the Research
Ethics Board of Brock University
(file #15-278).



If you have any comments or
concerns about your rights as a
research participant, please con-
tact the Research Ethics Office at
(905) 688-5550 Ext. 3035 or
reb@brocku.ca

To participate in this research
study or for more information,
please contact Susan Boyko by
email at sb08rg@brocku.ca
or my Supervisor
Dr. Sharon Abbey, the Principal
Investigator for this study, at
(905) 688-5550 Ext. 4308 or
sabbey@brocku.ca

Susan Boyko, PhD Candidate
Brock University
Department of Graduate and
Undergraduate Studies
St. Catharines, Ontario
E-mail: sb08rg@brocku.ca



Cancer Stories:
What Do Adults
with Cancer Need
to Know?

 <h3>Your Cancer Story Matters!</h3> <p>I am a PhD student in Educational Studies at Brock University. I have more than 35 years of experience working with people with cancer in cancer treatment centres; first, as a radiation therapist and more recently, as an adult educator.</p> <p>I would like to understand the impact of the information and education you received from your healthcare team, beginning with the diagnosis, during your cancer treatment and after your treatment was completed.</p> <p>Please take part in my PhD thesis research on: "Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning"</p>	<h3>Participants Must:</h3> <ul style="list-style-type: none"> • Be at least 18 years of age • Have a diagnosis of cancer • Have been diagnosed and treated for cancer in the Sudbury, Ontario area • Have completed active treatment; whether that was surgery, radiation, chemotherapy or a combination of these treatments • Be willing to talk about their experience of receiving the diagnosis, treatment and living with cancer • Speak, read and write in English <p>Participants will take part in at least two confidential interviews to explore their experience of diagnosis, treatment and living with cancer. Interviews will be arranged according to your availability at an agreed-upon location in the community, or by telephone. All information, notes and recordings will be kept confidential.</p> <p>I will also ask you to review a narrative I will write based on your experience story, so that I can share the story of your experience more broadly. Narratives will use fictitious (false) names to maintain confidentiality.</p>	<h3>Narratives:</h3> <p>Narratives or stories are a simple way to share information and knowledge. Telling a story is the basis of human communication. Hearing stories can allow us to better understand the lives of others and to learn from their experiences.</p> <p>To connect to people at the deepest level, you need stories.</p> <p>Robert McKee (1997)</p> <p><i>Narratives in Medicine</i>—The care relationship between a patient and a healthcare provider relies on trust. In the fast paced world of medicine, people with cancer may sometimes feel that their voice is not heard or that some of their questions are not answered. In order to build a trusting relationship, it is important that healthcare providers listen and act on the patient's story.</p> <p><i>"Effective communication, including active listening, expressions of empathy and sensitivity to the experience of the person affected by cancer, has been shown to improve psychological adjustment, adherence to treatment plans and satisfaction with care"</i> (Cancer System Quality Index, 2015).</p> 
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Appendix C

Recruitment Script

Hello, I'm Susan Boyko. I am contacting you about the interest you expressed in participating in my research study.

First, let me express my sincere thanks for your interest and my hope that your health will continue to improve since your treatment. I am a PhD student in Educational Studies at Brock University. I have more than 35 years of experience working with people with cancer in cancer treatment centres; first, as a radiation therapist and more recently, as an adult educator for cancer patients and healthcare professionals.

I would like to understand the impact of the information and education you received from your healthcare team, beginning with receiving your diagnosis, during cancer treatment and after your treatment was completed.

The title of my research project is: Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning

I hope this research may benefit you as you stop to reflect on the parts of your story that you wish to share. It may also benefit future cancer patients by influencing the information and education they receive.

If you are interested, I will ask you to take part in at least two confidential interviews to explore your experience of diagnosis, treatment and living with cancer. You may also share any journals, diaries, personal correspondence, stories, emails, blogs, photographs, or art objects about your experience if you would like at this time. I will arrange the interviews with you according to your availability at a meeting room at the Greater Sudbury Public Library, or by telephone. I would like to audio-record your story to make sure that I record it accurately and completely. I may also take notes if there are any problems with the recording or if you do not want to be recorded. You may stop your participation at any time without any penalty – I will destroy the audio recording of your story and any notes I have made.

I will ask you to review the transcripts from our interview, any notes that I might make and the narrative that I write that is based on your experience story. I will give these to you when we meet or send these to you in advance when we arrange connect by telephone.

I will keep all information you share with me, my notes (if any) and the audio recordings confidential. Narratives (stories) that I create with your help will use fictitious (false) names and locations to protect your privacy.

I will give you copies of my notes (if any), your story (transcript of the recording) and the narrative that I create. If you are interested, I will also share a final summary of what I have learned from this experience with you after my research is completed and my final report (thesis) is written in spring 2017.

I hope, after hearing this explanation that you are willing to participate. Do you have any questions about your participation in the study? Would discussing your experience be upsetting in any way? Do you feel ready to discuss your experience with me?

Appendix D

Letter of Invitation

May 2016

Title of Study: Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning

Principal Investigator: Dr. Sharon Abbey, Professor, Centre for Adult Education, Brock University

Student Principal Investigator: Susan Boyko, PhD Candidate, Department of Graduate and Undergraduate Studies, Brock University

I, Dr. Sharon Abbey, Professor, from the Centre for Adult Education, Brock University, invite you to participate in a research project entitled **Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning**.

The purpose of this research project is to understand the impact of the information and education you received from your healthcare team, beginning with the diagnosis of cancer, during cancer treatment and after cancer treatment was completed. If you choose to participate, I will ask you to share the story of your experience with the diagnosis, treatment and living with cancer. You may also share any journals, diaries, personal correspondence, emails, blogs, photographs or objects of art about your experience if you would like to at this time. You may meet with the Principal Student Investigator in at least two face-to-face or telephone meetings for the purpose of telling your story. All face-to-face meetings will take place at a meeting room at the Sudbury Public Library. You will also be asked to review transcripts of your interviews and a narrative written by the Student Principal Investigator based on your experience story.

The expected duration of your participation is approximately two to four hours, which can be spread over days or weeks as required.

This research may benefit you as you reflect on the story elements that you wish to share. It may also benefit future cancer patients by influencing the information and education they receive.

This research project is being conducted only in the Sudbury and surrounding community.

If you have any pertinent questions about your rights as a research participant, please contact the Brock University Research Ethics Officer (905-688-5550 ext. 3035, reb@brocku.ca)

If you have any questions, please feel free to contact me (see below for contact information).

Thank you,

Dr. Sharon Abbey
Professor
905-688-5550 ext. 4308
sabbey@brocku.ca

Susan Boyko
PhD Candidate
sb08rg@brocku.ca

This study has been reviewed and received ethics clearance through Brock University's Research Ethics Board (file #15-278).

Appendix E

Interview Guide

Title of the Research Project: Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning

Date:	Place:	Person Interviewed:	Interviewed by:
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I sent you a series of questions in advance of our meeting today to give you an idea of some of the things that I am interested in learning more about. If you are ready, I would like to begin with the questions. You can add more information as we go along. You can also share anything that you have written or created that you have brought with you today with me when we are finished. We can take a break at any time if you need one.

A. HEARING THE DIAGNOSIS

When you were diagnosed with cancer:

What was that like? What do you remember of that time?

How did you find out? Who told you? Where were you when you found out? Were you alone?

How did they tell you?

When you think about it now, can you think of anything that would have made a difference to hearing that news at that moment?

B. LEARNING ABOUT CANCER TREATMENT

When you met with the oncologist (cancer doctor) for the first time:

What was that like? What do you remember of that time?

Were you alone? What were you expecting?

How did they tell you about the kind of treatment they were offering you?

Did you ask questions?

When you think about it now, can you think of anything that would have made a difference to hearing about treatment and side effects at that moment?

Did you go to any group information sessions to learn about your treatment or how to manage your side effects? What was that like?

Did you meet with other specialists or healthcare providers to learn about your treatment and how to manage your side effects at this time?

Were there other ways that you learned about your treatment and what to expect? Did you speak with friends and family, look on the Internet, read books? What helped you the most?

C. AFTER TREATMENT – LIVING WITH CANCER

When you met with the oncologist (cancer doctor) at the end of your active treatment:

What was that like? What do you remember of that time?

How did you feel after your treatment was completed? What concerned you the most?

Did any other healthcare professional tell you about what to expect after your treatment was finished?

Did you feel prepared? Did you have unanswered questions? Did you know who to call?

Was there anything that the oncologist or other healthcare professionals should have told you about living with cancer after treatment but didn't? What would you like to tell others about this time?

Was your recovery after treatment better or worse than you were prepared for? Did you need more information? What did you need to know? When did you need to know it?

When you think about it now, can you think of anything that would have made a difference to hearing about what to expect at that moment?

Is there something you would like others to know about your cancer experience that might help them to navigate being diagnosed, treated and how to live with cancer?

D. CREATING A NARRATIVE

I would like to write a story about your experience to consider it in further detail. Once I write the draft version, I will ask you to revise it with me. Are you comfortable with this? Is there some part of your experience story that you would like me to focus on? What would that story be about?

Is there something about your experience that you wished would have been different? What would that look like as a story?

ADDITIONAL QUESTIONS

Who do you prefer hearing health information from? The doctor, the nurse, other healthcare professionals?

How do you like to receive information about your health? (Do you like to receive information verbally, in writing, in writing with lots of pictures? Do you like to receive information directly from a healthcare professional, in a group information session or from a peer?)

How would you describe your visits with the doctor? What is this experience like?

Is there anything else that you would like to add? Have you brought anything with you today that you would like to share with me? Tell me about this item. May I read it/make a copy of it/photograph it so that I can think about it while I write about your experience?

Thank you for trusting me with your story. I hope that you are not upset by sharing this information with me. How are you feeling at this moment? Please review the list of community supports that I have given you. You can contact these services if you feel upset or anxious because of our conversation. I would like to call you later today/tomorrow to see how you are feeling. Would that be okay with you?

Appendix F

Informed Consent

Date: **May 2016**

Project Title: **Exploring the Experiences of Adults with Cancer through Narratives: An Examination of Transformational Learning**

Principal Investigator (PI): Dr. Sharon Abbey, Professor
 Centre for Adult Education
 Brock University
 905-688-5550 ext. 4308
sabbey@brocku.ca

Principal Student Investigator (PSI): Susan Boyko, PhD Candidate
 Department of Graduate and Undergraduate Studies
 Brock University
sb08rg@brocku.ca

INVITATION

You are invited to participate in a study that involves research. The purpose of this study is to understand the impact of the information and education you received from your healthcare team, beginning with the diagnosis of cancer, during cancer treatment and after cancer treatment was completed.

WHAT'S INVOLVED

As a participant, you will be asked to share the story of your experience with the diagnosis, treatment and living with cancer. You may meet with the Principal Student Investigator in at least two face to face or telephone meetings for the purpose of telling your story and reviewing notes and narratives written about your experience. All meetings would occur at times that are mutually agreed upon, at a meeting room at the Greater Sudbury Public Library or by telephone. Any journals, diaries, personal correspondence, emails, blogs, photographs or objects of art that you wish to share as part of your story can be included. Conversations will be audio recorded to ensure the accuracy of the Principal Student Investigator's notes. Shortly after the interview has been completed, the Principal Student Investigator will give or send you a copy of the transcript to give you an opportunity to confirm the accuracy of the notes and to add or clarify any points that you wish. You will also have the opportunity to review a narrative written by the Principal Student Investigator based on an aspect of your experience that will be given or sent to you for review. Participation will take approximately two to four hours of your time, which can be spread over days or weeks as required. The Principal Student Investigator will give or send you a final copy of the interview transcript and the narrative that she writes to keep.

POTENTIAL BENEFITS AND RISKS

Possible benefits of participation include: Telling your cancer experience story can allow you to reprocess how you feel about the experience while you reflect on the story elements that you wish to share; you may make new connections, meanings and insights. What we learn from your experience may also benefit other cancer patients and families by influencing the information and education they receive in future.

There also may be risks associated with participation: Telling your cancer experience story may cause you to recall an unpleasant or distressing incident. If you become distressed you may stop the interview; the Principal Student Investigator can offer you information regarding psychosocial support available in the community that you may access as needed. Supports in the community include: your Family Doctor, Nurse Practitioner, Family Health Team, Aboriginal Health Access Centre and Telehealth Ontario. At the Cancer Centre you may contact: your Oncologist, Social Worker, Aboriginal Navigator and the Neuropsychologist.

CONFIDENTIALITY

The information you provide will be kept confidential. Your name or the name of anyone else mentioned in your story will not appear in the thesis or any presentation resulting from this study. With your permission, the narrative written by the Principal Student Investigator containing pseudonyms and/or anonymous quotations may be used. Shortly after the interview has been completed, the Principal Student Investigator will give or send you a copy of the transcript to give you an opportunity to confirm the accuracy of the conversation(s) and to add or clarify any points that you wish. You will also receive a copy of the narrative based on your experience either in person or by mail or email and a final summary of the project by mail or email when the student's thesis is completed in spring 2017.

Data collected during this study will be stored: Written records will be kept in a locked cabinet in a locked office in the home of the Principal Student Investigator. Digital records such as narratives; scanned pages from journals, diaries and personal correspondence; stories, emails, blogs, photographs or photographs of art objects and audio files will be stored on a home computer protected by a password. Data will be kept for 5 years after which time paper records will be shredded; digital records will be shredded electronically using a digital file shredding program.

Access to this data will be restricted to Dr. Sharon Abbey and Susan Boyko.

VOLUNTARY PARTICIPATION

Participation in this study is voluntary. If you wish, you may decline to answer any questions or participate in any component of the study. Further, you may decide to withdraw from this study at any time and may do so without any penalty or loss of benefits to which you are entitled. If you decide not to continue, any notes or audio-recordings made by the Principal Student Investigator about the information that you have shared will not be used in the study and will be destroyed.

PUBLICATION OF RESULTS

Results of this study may be published in professional journals and presented at conferences. Feedback about this study will be available from the Principal Student Investigator, Susan Boyko, sb08rg@brocku.ca when her thesis is completed in the spring of 2017.

CONTACT INFORMATION AND ETHICS CLEARANCE

If you have any questions about this study or require further information, please contact Dr. Sharon Abbey or Susan Boyko using the contact information provided above. This study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University (file #15-278). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project. Please keep a copy of this form for your records.

CONSENT FORM

I agree to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letters. I have had the opportunity to receive any additional details I wanted about the study and understand that I may ask questions in the future. I understand that I may withdraw this consent at any time.

Name: _____

Signature: _____ Date: _____

Appendix G

The Participants' Stories

A Silver Lining. Taryn's¹⁵¹ Story.

At age 31, I was diagnosed with an advanced stage of skin cancer called melanoma. I was working full-time as a respiratory therapist and an anesthesia assistant at a large teaching hospital in a large city. I was a single parent to my young son. My arm started bleeding one morning and I assumed that I had knocked it on something. There was a little white mole there. I didn't think anything of it because it was white and you know, skin cancer is black. My surgeon colleague offered to remove the little lump for me in her office the next day. I did not have much previous knowledge or personal experience of cancer, so when my surgeon colleague called me to her office urgently a few days later, I didn't understand why she was so concerned. She said, "I sent the bump that we took off your arm on Tuesday to the lab. It didn't come back with good news so I sent it to another lab just to check. It came back as melanoma and I'm very concerned."

I wasn't even in shock at that point because I didn't even know what melanoma was. I knew it was cancer, probably skin cancer, but I mean, no one dies of skin cancer, right? She asked me if I was going to be okay because I was by myself, if my son had a good relationship with his dad and if I had life insurance. I think that's when I started to be a little shocked. This is not the typical way that people find out about cancer. She ordered a series of tests for me over the next few days.

When I returned to my work area I said to my anesthesiologist colleagues, "Dr. A just told me I have melanoma and that it's bad." When I saw their faces, I realized that this might actually be quite a big deal. I had to go and pick up my son from daycare and go home. My parents were at my house, because it was my sister's wedding the next day. While we were

¹⁵¹ Pseudonym

preparing for her wedding, my sister asked about the bandage on my arm. I said, “Oh, they took off a bump and the doctor told me that it’s melanoma.” My sister is an x-ray tech who does CTs¹⁵², she’s seen staging for melanoma and she was more familiar with the disease than I was. She panicked. That’s when I thought, this is really not going to be good. I didn’t dare research it until after my sister’s wedding and my parents left to go home. I didn’t want to know until I had time to process it myself. Once I started reading about it, I learned that it wasn’t a pleasant diagnosis. Reading about it helped me understand what I was going to be facing. I know that the assumption is too much information scares people but it didn’t scare me. I felt the urgency to prepare for the unknown. I needed to know the statistics, the process and exactly what everything meant because I could prepare my son. Otherwise I would have been lying to him unknowingly.

Most of the information I received was procedural, not about the impact this would have on my life. It’s difficult to tell people what the outcome is going to be – cancer is so unpredictable. Most of my information came from what I was reading. I got a lot from other peoples’ experiences through message boards online about how their disease and treatment options progressed. I didn’t see an oncologist until four months later. By that time, I had already done a lot of research on my own.

Support. I think psychosocial support may have been offered but at a time I felt overwhelmed with facts and the time to act. Perhaps I wasn’t in a mindset where I could hear that offer or I didn’t think that I needed it. I realized that my son was going to need some support through all of this. I contacted a cancer support community that offers support to children on an ongoing basis. There was constant feedback from child life specialists as to how he was processing the information he was given and if he had questions. That really helped, and I found a community of other cancer survivors that I could laugh with, because in my personal life

¹⁵² CT scan – Computed Tomography scan

everybody took it so seriously. We could find some humour in dark things. You could never find that camaraderie elsewhere because you would make somebody cry when you brought it up. It is a very big job to protect your family members and friends from the pain, and keep them from feeling helpless.

My son was probably my biggest support because he wasn't scared. I was always very honest with him, even the day that he asked me if I was going to die. I told him that's a possibility and if I've got to go and do angel work, I'll still be around him. I think that because he believed I was being 100% honest with him he didn't have that fear of death and dying. He may have had anxiety but I always told him, "It's not happening today. We will know when it's going to happen and we can deal with that at that time. But it's not happening today and it's not happening tomorrow. It's going to happen over time." I think that alleviated his fear and he was more support to me than anybody else, because he didn't carry that fear or that look of pity on his face. When he came home from school he was telling me about his school day. It was normal. That was probably more support to me than anybody wanting to come and do anything else for me.

My best friend, Sandra¹⁵³ was really awesome. She helped with any logistical stuff that needed to be done and she also listened. We both agreed that it didn't help to say, "Oh, you'll get better", "Keep your chin up", "Keep fighting" or, "If you think positive." She just said, "Yeah, this really xxxxxxxx sucks!" Otherwise that puts the responsibility of failure or getting sicker onto my shoulders. I felt responsible for my disease when people said stuff like that.

My parents were also there for me, but because no parent wants to lose a child I could sense their fear, and that they didn't quite believe me when I told them that I was okay. They

¹⁵³ Pseudonym

worried. I didn't feel like I could fall apart with them. I needed to be strong for them, my family and most of my friends.

Treatment. Because I had a background in healthcare I don't think it was as scary for me as it is for most people. Treatment information was very factual. I felt very confident that I could ask for whatever I needed, whenever I needed it. They may have talked to me differently because of my background and the way that I presented myself. I wasn't an emotional wreck. I wasn't fearful of the treatment. I knew I had no choice. I did have a choice, but my choice was to do treatment. That may have been why emotional support wasn't offered, because I didn't need it. I do think that someone from supportive care should be part of the team when the patient gets the cancer diagnosis so they know who to go to with their emotions. I did get information from the cancer centre pamphlets, but it was very generalized, very low-level information that I could read in under 2-3 minutes. I had already surpassed that level of understanding.

I received immunotherapy called Interferon. There was some printed information on what the drug was, how it worked and the side effects. Treatment started in the first week of January 2007. It was 5 days a week, Monday to Friday every week for 4 weeks. I had a PICC¹⁵⁴ line put in to do those treatments. At the end of that month I did at-home injections 3 days a week of the same drug at a lower dose. I received written and verbal information about how to do my injections and where to store my medication. I was shown how to prepare and give myself the injections.

Treatment was pretty rough. They said that, "You're going to feel like you have the flu – but you're going to feel like you have the flu times 10." I felt horrible. I had a lot of pain, I felt like someone was wringing out my bones. At first I had a hard time getting pain control. I had to ask for pain control quite adamantly. When I managed to get them to understand just how bad I

¹⁵⁴ Peripherally Inserted Central Catheter

felt and how much pain I felt, they did offer me medication to help with that. Like most people, I didn't want to overstate my suffering.

I continued to work between surgeries, and while I was on the lower dose part of the treatment. About a month into the low dose treatment we realized that one of the side effects was taking over. I didn't even realize that I was very forgetful and couldn't focus at work. But my employer would not let me take more time off. The Occupational Health physician said that I had a contract to fulfil and I remember sitting there crying and saying, "I don't even know if I'm going to be alive next year! I take some time to spend with my son?" My family doctor finally arranged for my paid medical leave. She was a very big support through a lot of it. She would call me to follow up on test results and to make sure I was okay. The oncologist took me off treatment because I had the symptoms of early Alzheimer's. Although my twin sister was with me that day, I felt that I was supporting her more than she was supporting me.

My symptoms improved, life got back to normal and I went back to work. Around that time, I found the tumour just over my bicep. I showed it to my surgeon colleague who excised it for biopsy. It was a metastatic melanoma. She told me that this is not curative, this is disease management, something I'll have to deal with from now until the day it's going to be my demise. Because the margins weren't clear I was sent to see a radiation oncologist in December 2007. I was given some information, "Oh yes, you are going to feel tired after radiation, your skin may be burnt", but no one ever told me that I would have no skin and that it would be so burned that the pain was horrendous. No one seemed to know how to help me manage the wound. I did my own research and found materials that helped.

I couldn't provide appropriate supervision for my 5-year-old son at times and there was nobody else to call. No one pointed me in the direction of any help. I didn't qualify for meal

delivery or snow shoveling or child care programs. The Good Food Box was offered to patients with breast cancer free of charge but because I had melanoma I couldn't access that program. All my family lived elsewhere and my friends were busy with lives of their own.

Early 2008, I found another metastasis to the side of my chest. Again, excised and confirmed as melanoma. But it was decided not to do any systemic treatment at that time because my scans were still clear and the metastasis had been completely excised. About 6 months after that I found a lump in my neck, in my cervical lymph nodes. Biopsy again confirmed metastatic melanoma. Because the disease was in a lymph node and it had crossed over from the right side of my body to the left side of my body meaning advancing disease, the oncologist ordered scans to prepare for sending me for Interleukin immunotherapy in American City.

American City. The hematology specialist in American City said, "This is the only thing we have and you're not going to like it. You're going to feel like dying may be easier than going through some of the side effects". And he offered me the opportunity to say no, after all the information he gave me. He told me that the drug works for about 3%. And only 1% of that 3% go on to live more than one year. He added, "From there I can't promise you anything more than that. I can't tell you that this is going to work". But I felt that I needed to give it a shot because my son was young and there was nothing else.

I was supposed to have three rounds of the treatment in American City, travelling back to Canada in between in Spring of 2009. He wasn't kidding when he told me that it would be easier to die than to lay in that bed, because it was very painful. My mom told me later that the first time I walked in after treatment in American City, I looked like I just stepped out of my casket. Because I was pale, anemic and nauseous, my skin felt like it was crawling, my bones felt like

they were being crushed and everything was swollen. I had a Thrush¹⁵⁵ infection and the skin was falling off in my mouth right from the first treatment. They had a plan of action for whatever the side effect was and wanted to make sure that I was comfortable. By this point I had enough experience with side effects that I wasn't taking 'no' for an answer. I would get rigours with every treatment. I would feel cold and shake so much that I almost fell out of bed. The pain after the rigours, the sweating, you know, the hot-cold, it's crazy. The side effects were worse each time I got the drug.

After the second-round I found a new tumour on my chest. It was metastatic melanoma. My oncologists thought that if I was still able to grow metastases the treatment wasn't doing what it was intended to do. Plus, the tumours in my neck had actually grown. They weren't sure if they were bigger due to an immune reaction or if it was actually the melanoma growing. Treatment was stopped in August 2009 and there was nothing else they had to offer me. They could offer me pain or symptom control when I needed it. That's it. The oncologist explained that there were some new treatments being researched but none of that research was being done in Canada. He didn't expect to have access to those medications on a research basis for at least one year and he didn't think that I would be around for that time. That's basically how I learned that I probably had less than a year to live.

Life Happens. About three weeks later my father passed away in Small City and I missed my oncology appointment while I was away. My oncologist actually called me to make sure that I was doing okay, to see if I needed anything and reassured me that when I needed an appointment I could just show up or call. After that I tried to help my mother adjust to life on her own. My son and I moved back to Small City in 2011 to live with her. About six months later my mother was diagnosed with an advanced cancer. My life went from supporting her getting back

¹⁵⁵ An oral yeast infection

to work, to supporting her through cancer treatment and getting through the system. It was really just a distraction while I waited to die. I didn't know what else to do, not that that question ever came up because I had more than enough stuff to do! Time kind of went by!

And things didn't get worse. In the summer of 2010 I went to see my oncologist in Large City as a follow-up appointment. He said, "How are you feeling? You haven't called us, you haven't needed any help. Are you having trouble breathing or having a hard time swallowing?" I said, "Now that you mention it, I can't feel the lumps in my neck at all". Surprised, he palpated my neck and sent me for a CT scan. He waved me into the office later to show me the scan on the monitor. He said, "You know, they're smaller! In fact, your lymph nodes are back to normal size. I can't promise you that this means anything more than they're not there today. They may come back next week, next month, or next year. They may never come back. I can't tell you what to expect." He reminded me to focus on, "There's no evidence of disease today." It's cautious optimism.

Reflections. I am very fortunate that I had that 8 months that I lived here with my mom to help her go through what she went through. The funniest, the most ironic part is I would have never had that opportunity had I never had cancer. I can't say that having cancer was the worst thing in my life. It offered me opportunity to realize that life is short, you put your best foot forward every day and not to wait for tomorrow to spend time with people you love. While the dark cloud (fear of recurrence) is still there, my cloud has a silver lining.

Small City Challenges. Now that I am living in Small City, there have been challenges with getting medical care for both my son and myself. Without a family doctor or a local oncologist, when I had another metastasis, it was tough getting somebody to believe me that it was melanoma. In Large City my oncologist would take immediate action. It was finally excised

and it was melanoma. If I had a family physician that I had some rapport with when the node in my axillae popped up, I think they would've been more likely to believe me than the clinic doctor or the plastic surgeon that I had contact with. The family physician would have been my voice in the healthcare system, because my voice as a patient doesn't get heard as much as a physician advocating for their patient. Now I have a local family doctor and medical oncologist I can build a relationship with. I also had a CT for staging to see if that had spread anywhere else. That came back negative. I was told at the time of surgery that they were going to do genetic testing on that node because new research has come out and if they know the genetic type of melanoma they can better choose what treatment to use since there are new immunotherapy treatments. I lived long enough that research actually produced new drugs.

The oncologist in American City told me, "We don't need a cure for cancer, what we need is treatment that allows us to treat it like we treat high blood pressure or diabetes to make it a manageable disease that people can live with. If we could achieve that we could get some quality and quantity of life. You just need to live long enough to see that." The success rate for treatment for melanoma is much better now. Although people still die of melanoma, instead of a 3% chance of it working, it's more like a 60% chance of it working.

Information Seeking. I like online information because it can be visual, like videos, and you can interact with others who have gone through the same thing. You can read about what's coming up in future research, what you can expect and it's not on somebody else's time. If it's 3:00 in the morning and I've got a question I can search out that answer. I don't have to wait for an appointment to get an answer. It's information when I need it. I get enough information so that I know which question to ask the doctor. Instead of going in with a very generalized question I can go in with a very specific question.

Living with Cancer. Every once and a while, especially on Facebook, (I do belong to a few Melanoma things,) somebody will express their fear and I will tell them that in September 2016 I have been living with cancer for 10 years. I am still alive and I am currently “no evidence of disease”. There is always hope. It doesn’t mean that will be the case for everybody but just to know that it does happen. And I know of somebody else that is 25 years “no evidence of disease”. You can never say that that’s the end of you.

Final Words. Gratitude goes a long way, and it’s never your fault. Many people will say to a cancer patient, “Be strong! Because then this will all turn out okay, but you’ve got to keep your chin held high, and you’ve got to keep fighting.” You don’t have to be strong 100% of the time to make sure your cancer goes away. It’s not on you.

Because It Breaks Your Heart. Eva’s¹⁵⁶ Story.

I often think of my body. I’ve had two caesareans¹⁵⁷, a hysterectomy¹⁵⁸, my ovaries out, my appendix out, two colon surgeries and breast surgery – those are my battle scars. I often think about them. I don’t want to but I look at my body and say, “Eva, look you’ve done this and that’s why you’re still here.” I’ve known women who had breast cancer who said there’s no way I’m going to see anybody, I’m just going to die. It’s their prerogative to do that.

I’m Eva. I am a wife, mother and grandmother. I’m retired from the business field and busier than ever. The uterine cancer was really my first cancer. The surgeon just took my whole uterus out when I was 39. There were cells that were atypical, and I had fibroids. They got it quite quickly. My breast cancer was in 2002 when I was 51. After surgery, I had chemotherapy and radiation treatment. My first colorectal cancer (surgery only) I was 60 and the second one (surgery and chemotherapy) was in 2014, two years ago, when I was 62.

¹⁵⁶ Pseudonym

¹⁵⁷ Surgical delivery of a fetus

¹⁵⁸ Surgical removal of the uterus

Through all of this, I have always had a goal. The first one was to see my daughter graduate, the second was to see my son get married, the third was to see my grandchildren, my fourth was to see my daughter get married and now I'm waiting for her to have a baby. That's my goal now. I have to be here for my grandchildren.

There are two cancer stories to that I want to compare, my breast cancer (I call it my first cancer) and my colon cancers (I lump them together as my second cancer) because they were two totally different experiences. The breast story was not so good, but the colon cancer stories were good. What made them so different was the relationship that I had with my doctors and how much I had learned.

I can share my experience with other people now. At the time of my breast cancer, it was pretty scary. I found my breast lump and I went to four doctors before I got action. By the fifth doctor I was ready to kill someone. The radiologist wanted to compare my new ultrasound files with my old files. The clerk said it would take five days to get them sent over from the breast health clinic on Old Road. I said, "I'll go there myself and bring them back here." The breast health centre had them ready the next morning for me to pick up. Sometimes you really have to open your mouth! I'm not going to go the whole weekend and suffer not knowing if this is going to be good or bad. I went through a mastectomy, 6 months of chemotherapy and 25 shots of radiation for my breast cancer.

The surgeon who did my breast biopsy told me I had breast cancer and she said my whole breast had to come off. She was just old school. She wasn't mean but she also didn't give you much information, just the basics. Thankfully, as I left one of the nurses took me to psychosocial services. I was so shocked and frightened I don't think I could've walked out of the hospital! I

saw a very good psychologist who was with me for all my treatments. He would see me before my chemotherapy and he would calm me down so that the drugs could do their job.

The doctor I had for chemotherapy, Dr. B, my first medical oncologist, was very blunt, he didn't listen to me and he would not look me in the eye. I couldn't ask questions. My feelings were disregarded. I wasn't treated like a person. I thought I was going to die because nobody told me the success rates. I watched all these people die that I love dearly. My mother had cancer, she died; my sister had cancer, she died. I'm thinking, okay, I'm just going to die, right? Nobody told me that we caught it early, Dr. B never said anything to me about my prognosis. I was terrified with the breast cancer, not that I wasn't terrified with the colon cancers, but no one answered my questions. Whenever I went in to see Dr. B, I would always take my husband. He would talk to my husband but he wouldn't talk to me or even look at me. It was frustrating and insulting! He would say, "she", "she has", to Bob¹⁵⁹ while I'm lying there on the exam table. Finally, I just gave up and let him talk to Bob. I went by myself once and after that I said to Bob, "I'm never going there again without you." I had radiation treatments after the chemotherapy was finished. My radiation oncologist was so different! Even though she was all business she was supportive and I could ask her questions.

There were other problems because of the poor communication, too. Dr. B never told me to take my temperature. I was in the hospital, I don't know how many times, because my temperature went right off the wall. I nearly died once. Did he think I was smart enough to know? No one told me, maybe they assumed I knew. I was in the business field all my life and I never dealt with any medical stuff. I was getting nose bleeds, I didn't know why. I passed out on the floor, I didn't know why. Nobody told me. I went to see Dr. B and he said, "Oh yeah, your

¹⁵⁹ Pseudonym

platelets are really low. That's why you're getting a bleeding nose." I thought, that would have been nice to know beforehand.

He also didn't tell me I could be hospitalized for an infection. The nurses just said if your temperature is 38⁰ go to Emerge. One day I was about to have chemotherapy, and Dr. B said "You can't have any today." He didn't say why but he said, "You'll be back tonight." I didn't know what that meant. I was back in the hospital that night and I nearly died. He should have put me hospital right away. I was shaking so badly I woke my husband up. He brought me to Emerge and my fever was right off the wall. I went into a coma. They didn't think I was going to live. If Dr. B would have told me why taking your temperature was important, I would have listened. After that I paid attention to it because I knew, I had the experience.

With my second colon cancer, I had Dr. D for chemotherapy, and we were prepared. I had experience, good information and he talked to me. When I had chemo, and got a fever, Bob would take me into Emerge. In Emerge, as soon as I told them I was on chemotherapy they never even let me sit down. They put me right through Triage and I saw a doctor very quickly. It wasn't as terrifying as the first time, because I didn't know what they were doing with me the first time. I didn't know I was going to have to stay because I had a fever. I thought I was going to get some medicine, and go home. I know that sounds stupid now but, I didn't know because Dr. B didn't tell me anything. Even after, you know what he said? He said, "I've got good news and bad news. The good news is we think we got all of the bad cancer out of you. The bad news is we almost killed you while we did it." I think I was probably just a test tube to him. I was probably just a number. Maybe he didn't want to get involved or maybe that's not his job, I don't know, but it's got to be somebody's job.

My psychologist told me about a peer support group for women with breast cancer. It was a godsend! There were women there who understood what I was going through. I could share my fears and my problems with these women. I couldn't tell my husband and children about my fears – I needed to be strong for them. They needed to believe that I would be well again so that they could cope. I did other things to heal myself, too. I joined a dragon boat team with my daughter, explored my feelings in a journal and pictured my cancer as a dragon I could fight. I attended survivorship conferences and trained as a peer group facilitator. I even started another peer support group, *Women with Cancer*, for women with all kinds of cancer and in all stages because there was such a need. I didn't know it then but I was preparing for my next battle with cancer.

My colon cancer story begins with a routine colonoscopy. I've been going for colonoscopies probably since I was 35, because my mother, my sister, and my mother's sister, all died of breast cancer. I was told to have colonoscopies. I'm reaching 60 and I'm thinking, "Gosh, I must be okay now." I had breast cancer and all that chemotherapy. Dr. A, my general surgeon, had done all my colonoscopies, and after this one he said to me, "You have cancer." Bristling, I said, "No, I don't. How do you know? You're telling me I have cancer. You haven't even tested it." He said, "I'm 95% sure you have cancer. We'll talk about it later because we have to do something about it." While I was lying in the recovery room, fuming, waiting for my husband to take me home, a strange doctor greeted me by name. He said, "I'm Dr. E, a colorectal surgeon. Did Dr. A speak to you? You know you have cancer?" I said, "Yeah, I heard and I don't believe you and I don't believe the other guy. How sure are you?" He said, "I'm really sure. Listen to what I have to say. Who screened you?" I said, "Well, you'd be looking at her." He said, "You've done a wonderful job. Now you did your job, sit back, I'm a surgeon, let me do my job,

and I promise you you'll be okay." He took all the stress off me because I handed it to him. He took on that job. He told me he was going to take care of me, we were going to do it quickly, he knew my history, how frightened I was to have cancer again. He said, "Do you want to have the surgery? Do you want me to do it, or do you have somebody else in mind?" As soon as I looked into his eyes, I knew he was going to help me so I said, "No, I want you to do it."

Now that I knew I had cancer again I needed action! I said to Dr. E, "I can't wait a month for surgery. I'll go absolutely nuts. You know I've had cancer before." He said, "I am going to go look at my schedule right now. This is an emergency, if there's something I can put aside for one week, I'll redo my schedule. It will be done in two weeks." And it was. I was so relieved.

With this second colon cancer, when it was time for chemotherapy, a clerk called me with an appointment to see Dr. B again. Horrified, I said, "I don't want him." The clerk didn't know what to do. I said, "You're going to do something about it because he's not going to be my oncologist. I had him for 10 years." She asked why. I said, "I don't think I have to tell you that, but you can probably guess anyway. You might want to speak to Dr. C because I know that he's Head of Oncology and you can tell him what I said." I said, "If he wants to call me, I'll speak with him." I was more confident the second time around and I knew from the women in my support group that I had the right to ask for another oncologist. Flustered, she said, "Okay, I'll see what I can do and call you back." The next day she called to tell me I had exactly who I had asked for, Dr. D. I didn't have to wait to hear who I was going to see.

You know, the doctor has to look at you. He's got to see all of you. He can't just see the cancer. If he just sees the cancer, he won't be able to tell you anything, he won't be able to look you in the eye. I never got mad at anybody for telling me I had cancer, other than at myself. It's not their fault. But with Dr. D and Dr. E I felt that they were going to take care of me. I could sit

back. Wow. It's that personal touch. No question was stupid with Dr. E. That's a good doctor. Since he's young, I think he's probably been taught to treat the whole person. I've seen Dr. E outside of the hospital while I was shopping and he would say, "Hi Eva." Whereas I saw Dr. B for 10 years and I don't think he would have known me if he saw me in the street.

Dr. D came to see me in the hospital after I had my second colon surgery because he knew I was going to have to have chemo and I didn't even know yet. I think he was trying to start a relationship with me so that when I went to the office to see him I would be at ease with him.

When I did chemotherapy for my second colon cancer, I got c. difficile in the hospital before I went home. It just wiped me out physically after having the chemo. Dr. D wanted me to speak to Dr. F, the liver specialist, because they thought my cancer might have spread to my liver. I talked with Dr. F, and two days before my liver surgery Dr. E called me and said, "I had a talk with Drs. D and F and we've decided that you've gone through too much – you might not make it through this next surgery". Instead I went to Large City and had a PET scan. After the scan, they told me it wasn't cancer. I just have a beauty mark on my liver! Those three doctors were my team and they worked together. It was all arranged for me, I didn't have to do anything. Even though I was scared and angry because I might have cancer again, I was treated very well.

With my first chemotherapy Dr. B said to me, "You better get a PICC line for your chemo." I didn't get one because he never told me why I should have one. I thought a needle was going to be stuck in me forever. But this last time Dr. D said, "Eva, a PICC line will make sure that chemo won't burn your veins. If we put that in you can just keep it covered with your sleeve, even at your daughter's wedding no one will notice it." He was concerned with the wedding! I said, "I'm really afraid of that because I know it's going in my heart." He said, "It's very

successful.” He explained everything to me and I went in and had it done the next day. It was my decision.

Reflections. Each time I was told I had cancer again, and remember, this is twice now, I felt furious that I had to put my family through all that worry again. Why me, again? Cancer takes its toll on you because it breaks your heart. So, what helped me fight back? Aside from the relationship with my doctors, it was getting the information I needed, when I needed it, so I was in control.

Some things didn’t work so well. When I had breast cancer we did look at the binder and other materials. When I came home the first time, I came in the door and I had so much stuff in my arms, the binder and the books, and my daughter said, “You can’t possibly read all of that, Mother. Give it to me and I’ll tell you the finer points.” Mentally I wouldn’t have been able to go through all of that stuff. The binder was useful for some things but there was so much in it, I had to do just what pertained to me at that moment because I couldn’t keep anything more in my mind. So, give me the information when I need it.

While you’re doing the first thing, you can’t think beyond that. You can’t throw a bunch of information at a person right at the beginning, because they don’t hear anything at all. The first time around when I had the breast off, I didn’t hear a word, not a word. Small doses when a person is ready.

And give me a choice. When Dr. D told me about the PICC line, he said, “It will make it easier to take the chemo. Or you can get a port. The PICC line is probably better for you, but you have a choice.” He always gave me a choice. After the PICC line was put in, then he gave me the next information I needed.

I would really appreciate somebody asking me, “How do you like to learn?” and my

answer might not be what your answer is. Maybe the nurse could ask me, “Are you ready to learn? How would you like to receive this information? Would you like to see a DVD? Do you want to read about it? Do you want somebody to speak to you about it?” It would be good if you give people those choices. Give me a chance to come back and ask questions.

I like the doctor to tell me, one-on-one what to expect. Talk to me first and then give me the papers that go with what you just told me, in case I miss something while you were talking, I can go home and reread it. All my hair fell off both times I had chemo. With the breast cancer, I heard my hair would fall off from other people, but nobody told me my eyelashes and eyebrows were going to fall off or I wasn’t going to have a piece of hair on my body. My toenails fell off! Because most people don’t get all the side effects they just tell you about the most common ones. I happened to get some that were not common, but with my second colon cancer I had the information which made a big difference. I always felt prepared.

Do they tell you that these are going to be life-long things? Not really. Do they tell you that your memory’s going to be really bad but it’s going to come back? Not really, because I don’t think that they know. My memory is a big problem. I couldn’t remember my phone or PIN number. I didn’t drive a car for one year this time. I found it affected me more mentally because I’m older now. I do think they prepared me, but they don’t really know, because everybody’s different.

As for the Internet, I would never take anything there as the truth because I didn’t know what I was looking up. I would look something up, maybe find some questions and then ask a doctor. I love the fact that there is a patient library there. I know that now but I didn’t know that at the beginning. I can do my own reading when I want to. I was still so terrified when I went to the chemo group session, but at the same time I enjoyed the fact that I was hearing it from somebody else’s mouth.

People shouldn't have to think about cancer all the time. You do and anybody who tells you after they've had cancer that they don't think about it anymore is not telling you the truth. Because even when you're well, there's not a day or a minute that goes by that there isn't a cloud. Talking about it to others helps because your family gets really tired of hearing you. They want to believe that you're well. And you're going to tell them you're not well? Really, who do you have to talk to? Nobody. That's when it's important to have something like a peer support group. The women in my group say, "We wait for this meeting to come in and just blab it all out or go out for dinner and blab it all out." Then they go home for a month and it has taken some of the pressure off for a while.

Will cancer come back again? I really hope not but if it does, I'll be ready.

There Is Life After Cancer. Erin's¹⁶⁰ Story.

I'm Erin, mother and grandmother. I work as a cleaner in a long-term care home. My story starts when I was going to my family doctor, Dr. A, and trying to get him to listen to me. I was having very heavy menstrual periods and he just kept saying, "Well, it's because you're old and fat." I was only 48 years old! This had been going on for the past six or seven years. I had given up on getting Pap¹⁶¹ tests just because he was so dismissive of my basic complaints. It wasn't normal for me to bleed for seven days in a row. Eventually he insisted that he had to do a physical and a Pap test. The results came back as "irregular", but it's not unusual to have an irregular Pap. He did another one and that one came back irregular, too. When I saw the gynecologist, Dr. B, he repeated the Pap test. Again, it was "irregular" and it was repeated. So far, all four Pap tests have been "irregular". Not once did either doctor say it could be cancer. I continued through every day with my blinders on, not thinking about what all this might mean.

¹⁶⁰ Pseudonym

¹⁶¹ Screening procedure for cervical cancer

I had a cone biopsy¹⁶² and a colposcopy¹⁶³ and I went to the follow-up appointment with Dr. B alone. He said bluntly, “We’ve got all the test results back now. You’ve got cancer. There’s nothing more I can do for you. Have you got any questions for me?”

As soon as I heard the word ‘cancer’, the world basically shrunk down until I was looking through a tunnel. And when he asked if I had any questions for him all I could say was, “No, I’m good.” You can’t think because there’s just too much coming at you and when you hear the word ‘cancer’, it just means you’re dying. I had to go to work after this appointment. I don’t remember walking out of there or getting in the elevator. I got to my car and all I could think of is my children need to know because they knew I was getting these tests. But I couldn’t get it out of my mouth. We joke about it now, but I didn’t make *Mother of the Year* because I texted, “your mother has cancer” to them. I don’t remember starting the car.

When I got to work, I thought, “I can’t let anybody know. I’m not ready to talk about it.” I’m usually a very happy person and I wanted everyone to think I was fine. I stopped by the dietary department to see a very good friend. As I was about to greet her, she turned around, took one look at me and said, “What?” I thought I had put on a pretty good show for everybody so far. But when I saw her face fall I blurted out, “I’ve got cancer.” We both started crying and so did everybody around us. Everyone hugged me. She said, “We’ll get through it.” I kept working the rest of the day because I didn’t know what else to do. My biggest regret was not telling my oldest daughter by phone. She kept calling me but I couldn’t say it on the phone. She just left messages telling me to call her.

When I got home that night I told her and my other kids. The hardest thing to do was to tell my parents. I went to see them and my mother said, “Oh, so how did all your tests go?” I

¹⁶² Extensive cervical biopsy

¹⁶³ Magnified, illuminated, visual inspection of the cervix, vagina and vulva

said, “Not good, mom.” She said, “What do you mean, not good?” I said, “I’ve got cancer.” She swatted at my dad who was watching TV to get his attention and I told him. They didn’t know what to say.

It was tough waiting to get into the cancer centre. It was two weeks before I got a call from them; meanwhile all I could think about was, “Oh my God, I have cancer, I just want it out of me.” Everybody asked me what stage it was and I didn’t know. I’m sure they knew from the tests what stage I was in but none of the doctors would tell me. The gynecologist, Dr. B, said only, “You have to see the oncologist.” He could tell me I have cancer but he can’t tell me what stage it is? Dr. B left me without hope. It’s still the big “C” word. And you’re thinking, “It must be bad!” At least tell me it’s going to take a little bit of time to find out more, anything. But, all I got was, “There’s nothing I can do for you. My mind froze right there and then.

When I finally checked in at the cancer centre, I went through the registration routine and they handed me a binder. The binder is too basic and generic and it doesn’t give you what you’re looking for when you go there. Parking, who cares? Seriously, I’ve got cancer here. I’m dying, help me. Then I got to “the hurry up and wait chairs”. They told me to show up an hour early for my appointment and I just sat there. Eventually I got the smell of the place. I was nervous and shaking. I didn’t have anybody that I could bring with me because everybody was working.

The medical oncologist, Dr. C, said, “Why are you here? You need to see the radiation oncologist, Dr. D, before you see me. You’re basically wasting your time here because there’s nothing I can tell you until you see the radiation oncologist.” But that was the way it was set up for me! I waited another two weeks to see Dr. D, who is a wonderful doctor. This time my daughter was with me. Dr. D apologized for the delay in seeing me because she had to consult with a specialist. She said, “You have early stage cervical cancer. You’re going to have 35

external beam radiation¹⁶⁴ treatments, once a day for three months, and at the end we'll boost the dose with Brachytherapy¹⁶⁵, to hopefully shrink the tumour". I had both radiation and chemo at the same time. Diagnosis and treatment took almost a full year of my life.

I was sent to the radiation and chemo education group sessions. Since I had already had quite a few radiation treatments and some chemo, I thought it was a waste of time. It would have been helpful if I could have attended these classes to find out about radiation and chemo while I was waiting for my first appointments. The radiation presentation emphasized that lack of exercise and obesity brings on cancer in the group education sessions. I was horrified. I was sitting in a room full of people and I felt like they were blaming me for my own cancer because I'm fat. Group education is very impersonal and meanwhile, cancer is a very personal thing. I was very obese and I had a lot of self-hate already. That just made it worse.

I was diagnosed around October which is breast cancer month. When I walked into the cancer centre the displays were pink. Cervical cancer is teal. Breast cancer is a popular cancer but there was a lack of information and attention for cervical and other cancers. Were people with breast cancer going through more than I was? I felt like I should apologize to everybody for being there. I didn't have anyone to talk to and I couldn't relate to anybody. I didn't know where to go to ask, "Is this the way I'm supposed to feel?" I didn't find out about psychosocial services until I was done treatment. I just kept showing up for my appointments, and going through the motions. I felt so lost because I was not in control of my health. I did what I was told because the doctors told me this will save my life.

My external beam radiation treatment experience was also humiliating because of my weight. They had to lift my large stomach and tape it to hold it in place. I also had to have just

¹⁶⁴ Several beams of high-energy x-rays focused on an area inside the body

¹⁶⁵ Small sources of radiation temporarily placed into the body by special applicators

the right amount of fluid in my bladder for treatment. When I got called in, if I didn't have enough, then I had to go back out in the waiting room and drink more water. I started calling it my *walk of shame*. The worst days were chemo day because I had three bags of fluids in me. If I voided too much I had to drink again. I'm sure the other patients were thinking, "You didn't drink enough?" as I walked back and forth.

People offered to come with me to my appointments but I felt like I had to entertain people if they came with me. My girlfriend, who has since passed from breast cancer wanted to come with me but I never asked her to come into the treatment rooms because she had already been through enough. When I got home she would ask me how it went. She was my source of information. I would rather ask her questions because this was her second round of cancer and she really understood. She could explain what was happening.

Brachytherapy was a terrible experience. They brought me into the barren treatment room. You have equipment, a light, a bed and nothing. It looks like a torture chamber. The nurse showed me the rods and the rest of the apparatus. She told me that I would be lying on the small table and the rods would be inserted into my cervix so the sources of radiation could pass into them, and the tubes would go in my rectum. It didn't sound really bad. But they didn't give me any idea of what it was going to feel like. I found out I had fibroids¹⁶⁶ in my uterus with my first Brachy treatment when Dr. D had to push one of the rods through a fibroid. Nobody had ever me I had fibroids. When I screamed out loud, she immediately ordered medication. They continued with the process but they did not tell me what they were doing. I felt totally violated. People around you in this dark room, tubes push into you and someone grabs at your arm. It felt like a free-for-all. I was scared. The second time I had Brachy a different nurse said, "You let me know

¹⁶⁶ Non-cancerous tumours

if you have any pain and I will make sure you're comfortable." She was so absolutely awesome. I felt nothing. It was the best Brachy, if you can imagine it.

My third one, I had the worst nurse ever. She refused to give me pain medication even though I was telling her, "Look, I'm in pain. I can feel this, it hurts." I explained that the second nurse and I had a system that worked really well. She refused and walked away. Everybody left the room, the Brachy treatment started and tears were rolling down my cheeks. When one of the radiation therapists completing the treatment came in to check on me, I told her the nurse refused to give me pain meds. She said, "That's too bad," and walked away and restarted the treatment. Nobody gave me more pain medication.

At the end of the treatment they put me in a little recovery room. The nurse I had for my second Brachy stopped by to see how the treatment went. I said to her in fury, "You know what that bitch did? She left me in pain the whole entire time. The only time I got pain meds was when the doctor was in the room." The nurse was sympathetic and apologetic. I didn't know that I could have reported that uncaring nurse. You're not told that you have rights if someone's mistreating you and refusing you meds. That's why I said the Brachy is torture. It's not like I was a drug addict. It may have saved my life but it was absolutely barbaric.

I saw Dr. C again to discuss starting chemo treatments. He told me I was going to have eight or ten, I can't remember the exact number. My brain tends to chuck traumatic stuff. I have to write everything down and my memory has gotten worse since I've had the chemo. Dr. C was the doctor who finally told me I have a tumour. I said, "Tumour? I have a tumour?" He looked at me like I was stupid. He said, "Of course you have a tumour. That's what cancer is." I said, "Oh my God. I've got a tumour. Nobody told me it was a tumour." Because they said they were *scraping off cells* I'm thinking I've got cancer *cells*, not a tumour. I was in shock and he just

continued talking about the chemo. I heard from other patients that he's not known for having the best bedside manner, that he is very blunt and offhand. But he did okay for me.

Luckily, I didn't have to have major chemo. I didn't lose all my hair and I wasn't going to spend months nauseated. The chemo nurses made sure I brought all my meds with me and took them before the chemo started. They would always check on me and ask, "How are you feeling? How are you doing?" The chemo nurses were exceptional. The care that I got in the chemo room was amazing.

I met someone who had cervical cancer in the chemo room. I told her, "There is hope. I had it." Her face lit up and she really relaxed. I told her it was going to be rough and how to manage Brachy. I said, "Insist on getting medication for that pain. Do not let them leave you in pain. They did it to me, don't let them do it to you." People need to know they have rights when they're a patient. If something is hurting, you have the right to have it not hurt. She said, "Thank you so much." It felt so good to meet someone else with cervical cancer, that I wasn't alone. I didn't have to feel odd because everybody else was in there with either breast cancer or a more severe cancer. You almost want to whisper, "I have cervical cancer."

I think it was about a year after I found a support group that is very unique, because it doesn't matter what kind of cancer you have. There's no colours. We're women, we've had cancer and we need to talk to other women about it. I heard about *Women with Cancer* through my girlfriend who has passed. She was attending the meetings and she suggested that I go too. She knew I wasn't ready to talk about what was going on yet. My girlfriend was my symbol of hope, strength and survival. I was just more focused on getting to and from the treatments and trying to hang onto everyday life.

I was struggling. I wasn't getting any money in while I was sick and I needed money for

food. I tried welfare. That was the most humiliating experience of my life and the woman had to apologize because they couldn't help me. I got cut off my benefits because I attempted to go back to work during treatment. I ended up with full blown lymphedema¹⁶⁷ in my legs and I could not walk. By then, I had already sold my house because I was sick and I went into an apartment. Thankfully, I had some really good people behind me who raised some money at work so I could buy food and a couple of friends did extra grocery shopping. That kept me going for the four months I was off. I could not find assistance anywhere. My parents helped out where they could, but I wasn't going to put them in the poor house.

I didn't find out about psychosocial services until almost the end. I could have used it at the beginning to help me process everything when I was on autopilot. If you do have any questions, you don't know who to ask – is it the oncologist, family doctor, nurse? I just shut down because it was easier. I dealt with it as best I could, but I got through it.

I would say try to get the clinic out of the experience and make it more friendly. It doesn't seem very personal when you're looking to feel normal and you know you're not. The personal touch is missing. When you think clinical, you take the humanity out of it and make it very rigid and very structured. But when you start introducing stuff to make people feel human and feel like they're going to be okay, even though a lot of them aren't going to be okay, that's something. Put the humanity back in it, because we all have feelings.

I learned early on to take the Internet with a huge grain of salt. My daughter looked up cervical cancer. The Internet makes it sound worse than it is – you're basically going to die from it, and my daughter was just beside herself. It upset her more than it helped it her.

I told my daughters, "You've got to be vigilant and never mind how the doctor makes you feel." My family doctor, Dr. A, made me feel bad for asking for a Pap test. It got to the point

¹⁶⁷ Swelling in tissue as fluid builds up because of obstructed lymph ducts

where I just didn't bother. One day I went in to tell him about the heavy bleeding. He was yelling at his secretary and then he opened the door with such a push I could feel the vacuum. He said, "So what do you want?" There's no way I was going to talk about my nether region that day. I asked for a prescription instead.

I see Dr. D in follow up for my cancer. I go back to my family doctor for anything else. I've had gastric bypass surgery and I'm a much smaller, healthier person. I have confidence in Dr. D because she's been awesome with letters for insurance companies, for my work, everything. She's gone to bat for me. I'm still getting the Pap test every four months now. Dr. D is keeping a very close eye on it, which makes me feel really comfortable. If she was being dismissive, I would have shut down because that's my thing. Yeah, I've still got the playground in there, is there a chance that it's going to come back? Sometimes I feel like I still have the blinders on. Maybe I prefer it that way; if something does pop up, it's like a new surprise for me. I don't really know what to expect after I'm done all this.

I would say to new patients, "Even though what you're going through is horrendous, *there's life after cancer.*" The fear becomes a distant memory but it is always there and it never goes away. When I hear that somebody else gets cancer, as a cancer survivor, I get into a, "You can do it" mode. I got really tired of hearing 'You're a fighter' and, 'You're so strong. I say, 'I survived it.'

My family was relatively untouched by cancer. My grandfather did have lung cancer but when he passed away, it was quick and there was no treatment. He was the only one I've known of. Then I got it, my dad got it and my dad leaned on me to support him. It felt good to be able to help him, because I understood. So, when he was palliative and passing away from it, I was okay with it, even though it was my dad and I love him dearly.

Final Words. If you have cancer, there's some common questions. The Canadian Cancer Society has information books for most cancers. But all cancer should be recognized, not just the more popular ones. If you have cancer, you have cancer. Cancers are different but people tend to have the same concerns and questions.

When I heard that you wanted to hear cancer stories, I came forward so nobody else would have the experience that I had, like feeling stupid when the doctor tells you have a tumour because you didn't know. I really appreciated this because you've had the background in it. So, you get what I'm saying, whereas some people "Oh that's horrible. Oh well." After all this, it felt so good to tell somebody all of it, like from beginning to end. And it's meant a lot, thank you so much.

She Is My Saviour. Loraine's¹⁶⁸ Story.

My name is Loraine, I'm 35 years old. I was hearing impaired as a baby so I had a harder time understanding everything. I've had four operations for my ears and I still have difficulty hearing. With my learning disability, I always needed more help in school. Later, when I took a *Cooks Helper* program at *French College* I learned that I am a visual learner. It really helps if you give me something in writing so I can go back to it later.

My mother is the most amazing person in my life and she is always there to support me. It was my mother who noticed I had a large swelling in my neck. She said, "I want you to go get that examined right away. I don't care if you have to go the emergency room, your family doctor or to a clinic." I was having all kinds of symptoms. I was more prone to colds, I was stressed and tired, having a lot of headaches, dizziness, even weakness so that I had to sit down a lot. My employer at *French College* was surprised because once I even had to lay down for a minute. I thought maybe I had allergies or something like that.

¹⁶⁸ Pseudonym

My family physician examined my throat and both sides of my neck. He ordered a blood test and an ultrasound. A friend went with me for the tests this time because my mother was in Toronto visiting my cousin. My mother tries to go to all my appointments with me so she can make sure that I understand. I felt pretty anxious. But the ultrasound and the bloodwork didn't really tell him anything. He referred me to a specialist for ears, throat, nose and neck. My mother came with me to see the specialist. He reviewed everything with me, examined me and said he wanted to do a biopsy to find out what it was. I saw the doctor in mid-August and at the end of September I had a biopsy at the hospital.

The biopsy was a very painful procedure. They inserted a camera into my left nostril just to look inside my throat and my vocal cords. He took a sample from the middle of my neck and took pictures with the camera. He asked me to make a couple of sounds so he could see if certain things were working.

When I went for the results he told me that he still didn't know what it was but the next step would be surgery. He didn't tell me more than that so I don't know what he thought it was. We had a pre-op visit on the 10th of January. They took my weight and checked my vital signs to see if I was healthy enough for surgery. After that, there was more blood tests.

I had the surgery on the 14th of January, because I remember the 13th was my last day at work. My employer asked me if I wanted to take some time off work, but I said I would work right up to my surgery. I've worked in the kitchen at the *French College* for almost 13 years.

We had to be at the hospital for 6:30 in the morning. Surgery was at 9:00. My surgery lasted four and a half hours because there were complications. I had a knot in my wind pipe and the massive veins in my thyroid caused a lot of bleeding. The doctor told me they found three tumors and said that they took out the whole thyroid gland. After the surgery, I was on heavy pain and calcium medication.

I spent about five hours in recovery because they had no bed for me. After that they put me to a surgical day area. As soon as I was starting to feel better I was moved to another unit. I had a drain, and dissolving stitches. It actually healed pretty good. If I needed something my mom was there to help me. A lot of people came to visit me while I was in the hospital.

When I was going home, the nurses showed me how to take care of my incision and it was pretty easy to handle. I couldn't lift, I had to have someone come to my house and do my house cleaning and do my meals because I just wanted to sleep after surgery.

After the operation, the surgeon sent everything he took out for testing and I went to the cancer centre for the results with my mother. On January 26th, 2016, I found out that I had thyroid cancer when I had my consultation with the oncologist. There were three doctors that day: there was the surgeon who did my ear surgery, the surgeon who did my thyroid and the radiation oncologist. The oncologist told me that what they removed from my neck was 95% cancerous. I took it quite hard and I think even the doctor was surprised that I was pretty upset. The doctor told me in a kind manner because he didn't want to upset me, but it was very difficult. My mother was also in disbelief that I had cancer. I didn't know how to react, I didn't expect to hear I had cancer. I just felt a big shock.

I've heard that when other people get told they have cancer they are just in disbelief, too. But I wasn't even angry or frustrated, I just accepted what I had. It took me some time. I knew I could get through it no matter what, because I know that I'm a strong person and I can get through anything. I've had some hardship in my life, like bullying in school and an abusive relationship, and I got through it.

The oncologist wanted to do a scan of my thyroid, an iodine test. I couldn't have any salt before the test. I drank a radioactive solution and they told me what I could and could not do

after the test. I went for a CT scan. I had to fast for two hours.

I had another surgery in March because they found more cancer. I got a letter to meet with the same two surgeons on March 1st for the pre-op and my mom was supposed to be there with me. But she couldn't go. I had to go by myself so that was a little challenging. I had to meet with the anaesthesiologist. He told me what they were going to do. For both surgeries, I had a pretty good experience.

The second surgery was very difficult. It was six hours. I was in hospital for nine days, and three days in intensive care. They had to keep me asleep for a day so I wouldn't get an infection. I had to be fed by tube. I had a catheter for the first time. My mother has had catheters from numerous operations she's had. She explained a lot of things to me and answered my questions.

My second surgery wasn't as painful but there were still the side effects and it was hard because I went up and down with my emotions, it's like a little wave. I had some good days and some not so good days with my energy and emotions. I was referred to a social worker and a dietitian at the cancer centre. The dietitian gave me information about what to eat and what not to eat. Because I had been referred to a social worker I did get some funding on two occasions. Because when you don't get any unemployment insurance or you don't get any ODSP¹⁶⁹ for awhile, it does affect you. Four months later I had the other radioactive drink, the thyroid ablation¹⁷⁰ to make sure all my thyroid was gone. I went back to work September 6th, 2016.

They've never given me any information about what I can expect now that I don't have a thyroid anymore, but I know that I have to take thyroid medication every day. Since I've had my ablation treatment I've noticed I'm more thirsty. They didn't tell me that was a side effect but I

¹⁶⁹ Ontario Disability Support Program

¹⁷⁰ Radioactive iodine given to destroy or ablate residual thyroid tissue

think I should ask my doctor about that. I feel a lot better than I was before. I'm a little bit more alert but it's just that I have to practice with memory. When I'm at the college if I have to take a telephone message or report that something's missing, I write in my book. And sometimes my employer will joke with me, "Oh, you're writing me a love letter, aren't you?" He knows that it just helps me with my memory.

I am a little saddened now because I have more problems. A couple of days after I got out of the hospital I ended up having a seizure. It's not because of my thyroid. But about two years ago, I got really sick and ended up having a seizure. They didn't give me any seizure medication but they gave me antibiotics to lower my temperature and medicine to ease my headaches. But it happened again after March 13th this year. Someone called an ambulance and I even bit my tongue. So, it was pretty bad. They kept me an hour and a half in Emergency and my mother brought me home. They didn't do a full exam but the doctor did give me some seizure medicine when I was at the Emergency. I was very surprised, because last time the doctor didn't give me medicine for seizures.

Two years ago, he thought it was my anti-depressant medication that caused the seizure. Test didn't show anything. I was very surprised. He did an EEG but I think that he didn't tell me the full story that time. So, when I had this second seizure and we met with the doctor he looked at it again and this time he told us that I had an abnormality of my brain. If he would have told me that before maybe I would have got proper medical treatment sooner, maybe even monitored it a little bit more. Medication affects me quite a bit.

So now I have a lot of medications and it's confusing. I've been fighting with the doctor and the pharmacy to get my refills when I need them. Sometimes I don't know who I'm supposed to see for what. I'm due to go for another follow-up with the oncologist in November.

If I had a concerning symptom about my thyroid, I would call the oncologist's nurse. But I have a problem with knowing who to go to for other problems. I don't know if my counsellor talked to my doctor's nurse. I did go for a blood test with my family doctor to make sure that my medications are working. It must have been good news, because I didn't hear anything.

I do see a specialist for my seizures, but I would say that my family physician knows the most about my health. At first, we didn't have a very good relationship but it is better, maybe because of my mother. I guess he's monitoring me because the oncologist was going to send him a letter to him with all the information. My counsellor at the ODSP helped me organize and pay for the cost to have a volunteer driver. If I need to go to the appointments and my mother can't pick me up, then I get the volunteer driver to take me. So, it helps me get around.

The doctors usually speak to both me and my mother when we're together but I usually just listen to the doctor. He pretty much makes eye contact with both of us. Then the doctor will ask me questions about how I feel. They've never really asked me how I like to get my information or if I understand. My mother always has a lot more questions. She is my voice. If I said that I didn't understand my mother would explain what he said to me but I will ask the doctor, too. Having my mother with me helps me and the anxiety level is not as harsh. But when I'm by myself, my anxiety level hits the fan. I worry that I might not understand or I might forget something.

Throughout my treatment, I got nothing but love and support. Everybody's been very supportive, even the president of the *French College*. I went to see the doctor on September 15th. I'm doing well and right now they don't think there's any more cancer. I was in so much disbelief that I had to stop the doctor in the hallway. The doctor sent me for another blood test to make sure everything's okay. They want to see me back in November, every three months. I'll get the volunteer driver to drive me.

I'm joined a support group called *Women with Cancer*. It's been really great. I'm very happy that we have a group like that to help women with all kinds of cancer and any age group. When I went to the meeting the first time it was one of the most beautiful meetings ever, I just wanted to cry. I heard about *Women with Cancer* from my counsellor. It is so important. When we meet, people feel they can say anything without being criticized or being judged. It feels very good just to talk. Because if you just leave everything inside you feel anxiety.

My church group has Jeanne D'Arc as their symbol. I am very fond of her too, she is my saviour. She's very special to me, like my mother. People give me compliments about my hair and tell me I look like Jeanne D'Arc. She's one of my favourite saints. She gives me strength. And I volunteer for a woman's centre, too. I want to help other women who have gone through things like I have.

My button necklace is like a circle of friends. You know, every person is unique in their own way. The necklace says, "Wow, you've got very good friends and they're there for you." And my scar fits with the circle of the necklace. I told the women's group at church, "I didn't have to go to a tattoo parlour just to get this circle done." My friend said, "Well, it looks more like a smile to me."

There's Always Hope. Holly's¹⁷¹ Story

I was 17 and in my last year at a small town high school when I was diagnosed with cancer in 2011. I was active in sports, an honours student, and I worked part-time at a video store. I planned to graduate and go to university to become a radiation therapist.

It took several years to get the diagnosis and treatment. In November 2007, I tore the muscles in the left side of my neck in a high school sporting event. By Christmas break, I noticed that I had a large lump on my neck that was bigger than a marble, but smaller than a golf ball. I

¹⁷¹ Pseudonym

showed it to my dad when he got home and he figured it was from hurting my neck back in November. Once the doctor at the walk-in clinic heard I had hurt my neck before he brushed it off as the result of my injury, too. Over the next few years whenever I went to the walk-in clinic and to the Small City Emergency for other things, I'd ask the doctors to look at it. All the doctors who saw it said that it was probably nothing to worry about.

In the winter of 2010, I went to work in Western Province. I met a chiropractor who looked at the lump in my neck and heard my story. He said, "It's nothing like I've ever felt before. When you get home, promise me that you'll go get it checked out, and you won't take no for an answer until someone takes you seriously." I got home in the middle of summer, went to another walk-in clinic and said, "This lump has been here for three years now. It doesn't hurt, but it's getting bigger." It was now the size of a golf ball. You could move it around a little. The doctor said, "Well, even if it's nothing, it's ugly. We'll get rid of it." She gave me a blood requisition form, and booked an ultrasound. The ultrasound and the blood results didn't really show anything but she sent me to a general surgeon in our town who requested a CT before I even got to see him.

I had the CT done, and all my results were sent to the surgeon. When I met him in October 2010, he said that he had seen the images and he didn't think it was serious. He didn't want to biopsy it separately, but he gave me two options for removing it. He could freeze the area, right then, with me sitting on the table in a review room and cut it out, or they could book me into day surgery under general anaesthetic. I didn't like the idea of being cut open on the table so I opted for the day surgery. The surgery was booked for December 21st, 2010. My dad knew that I was trying to get it removed, but he didn't go to doctors' appointments with me because he didn't think it was anything serious. My mom and my brother had come up from the

States for our family Christmas. At the hospital, the surgeon went over the game plan with us again. He would do the biopsy and surgical excision at the same time.

My mother said that afterwards, the doctor told her in the waiting room that the surgery went fine and there were no complications. He said he removed all the lump with some excess tissue around it and I would be fine. I would have a tiny scar at the back of my neck. I was sore when woke up but with some painkillers to help for the next few days, I enjoyed Christmas with my family.

On January 17th, 2011, around 6:08 p.m., I was at work at the video store. When I started work I forgot to turn my phone off and it was ringing. As I started to turn it off, I noticed the hospital number on the display. I wondered if something had happened to my dad. I answered, and it was the surgeon at the hospital. He didn't ask me if it was a good time to talk, and he said, "Is this Holly? We have the Pathology results back from your surgery. You have a malignant cancer tumour called spindle cell sarcoma." He also said he was leaving for vacation tomorrow, he was no longer my doctor, that somebody at some cancer centre will contact me at some point, and hung up the phone.

I was so shocked I couldn't breathe. I didn't know what *pathology*, *malignant*, or *spindle cell sarcoma* meant. But I heard the words, "tumour" and "cancer" and they really resonated with me. I remember just standing behind the desk at the video store, then realizing that my manager was standing in front of me. He asked me if I was okay and if I needed to sit down. He said, "You look like a ghost." I said that the surgeon called and told me I had a tumour and cancer. The next thing I remember, we were in the back room and he had me sit down.

I kept repeating, "Somebody needs to be on the floor. We can't leave the store unwatched." But he said, "That's not what matters right now. We have cameras. If somebody

comes in, we'll know." He tried to convince me to go home, and I said, "No, I'm going to stay. I'm just going to call my dad and tell him." I called my father and said, "Okay, the doctor just called me and told me I have cancer. Should I come home?" My dad said, "No, just stay at work. We'll talk about it when you get home." My shift was until midnight. I was really close with my boyfriend at the time so I sent him, this is horrible, a text message that read, "The surgeon just called. He said what he removed was a tumour and I have cancer. I'm going back to work without my phone." I turned my phone off, put it in my locker and I went back to work for another six hours. When I finished work, I turned my phone back on to find multiple messages from my panicked boyfriend. He and his parents were freaking out. I called him, repeated what the doctor had told me and went home.

When I got home I knocked on my dad's door and woke him up. He said, "I'm tired. We'll talk about it in the morning." When I got up in the morning, I went to see him again. This time he said, "I'm running late for work. We'll talk about it when I get home." Maybe he was scared but he didn't work till 8 am and it was only 6 am!

I don't think I'd processed it. He took it out, there's nothing left, but it's cancer? I don't know how I functioned, but I did. I went to school. The hall monitor came up to me and said, "Are you okay? You don't seem talkative." I waited until class had started before I told her. We sat down in her office and she asked me what I knew about it. I tried to Google *spindle cell sarcoma* the night before but all I could find was about tumours in dogs. We both tried Googling it again with no luck, because we didn't know how to search the Internet properly. When we walked past the biology class I was supposed to be in, the teacher came out and asked me why I wasn't in class. I remember breaking down for the first time as I told him about it. I said, "You're a biology teacher. You have to know what this means." He had knelt to look up at me,

and he said he didn't know. They both asked me why I was even at school today. And I said, "I didn't know what else to do. I don't even know who's going to contact me, where they're from, or when they're going to call."

At some point, I received a phone call from a cancer centre in Large City, saying that I had an appointment with Dr. A, the day and time, and I needed to bring in copies of any CT scans and test results that had been done. I didn't have any copies. I went to the walk-in clinic first. They said that they didn't have that information and they sent me to the surgeon. I went to the surgeon's office, which is located right next to the hospital. I explained who I was. The receptionist said, "He's not your surgeon anymore so we can't help you."

Throughout my illness people either treated me like I was just a kid and I didn't know anything, or they would only speak to my parents. Up until this point my parents had not been involved other than the day of my surgery. When I told my dad that they didn't take me seriously he went to the surgeon's office. They sent him to the Health Records department of the Small City hospital. He waited at the hospital for hours to get a copy of the scan on CD and my test results.

I went to the cancer centre in Large City with my dad on February 8th, and the surgical oncologist, Dr. A asked me what the other surgeon told me. I repeated that he said I had a malignant form of cancer, he had taken everything out at surgery, plus some extra. He said, "Based on the image information you brought, and the Pathology report, that's not true. The tumour was not cut out cleanly and there may be some left behind." He couldn't tell me if all the tumour was removed! I needed more imaging. They managed to get me a booked appointment for a MRI on March 8th. That day, I had a chest X-ray and a CT scan at one Large City hospital and an MRI at another Large City hospital. A family friend who became like an adoptive mother

took me for these appointments. At this point in my story, my biological mother did not know the results of the first surgery, and my dad didn't want me telling her. The news that I had cancer didn't seem to bother him. He made comments like, "Great, now we've got to go to Large City." He insisted that I keep going to school and not let anything affect me.

After the upset of my diagnosis in January the school agreed that I didn't have to write the first semester exams. My grade for the classes would be recalculated and averaged out, and I accepted that grade. I continued going to school as if nothing was happening.

After the imaging was done March 8th, 2011, my dad came with me to my appointment with Dr. A to go over everything. Dr. A said that they couldn't tell from the images what, or if there was anything left behind. He told me the best option was radiation treatment, followed by another surgery. I asked, "What if we did nothing?", because I so wanted to believe that everything was taken out. He said there was a chance I was fine but since he didn't do the first surgery, he couldn't assure me about anything. He recommended radiation and surgery. I had no idea what radiation treatment was or what the best option was for me. I could only trust my doctor so I said, "Whatever you think I need to do, let's do it." I signed the papers that day.

I had to come back the next day to have a CT Sim done as well as other appointments. I didn't know what a CT Sim¹⁷² was since all this happened before my radiation therapy education. The next day they started by making a plastic mask to hold me still for treatment and I learned I was claustrophobic! After that, they did the CT Sim and we met with the surgeon. He told me that I might get a phone call next week with a start date. We went home and the next day, Friday, and I got a phone call saying that I started on Monday.

My dad decided that now there was a plan for treatment we could tell my mom. He called her to tell her. My mom lives eight-and-a-half hours away and in another country but she came

¹⁷² CT scan that is done for planning radiation treatment

for the first week of treatment. On the second day of my radiation treatment I met the radiation oncologist for the first time. I had been given one generic book on radiation treatment and side effects and another one on eating healthy. The book was not broken down into site-specific effects. I read that radiation can cause infertility. I didn't know that the radiation would affect only the area it was targeting. That was overwhelming! As far as any classes or support groups, I wasn't offered anything. Or if it was offered to me, it might have been offered to me through my mother and she never told me.

I saw the radiation oncologist once a week for the weeks that I was on treatment to check how I was doing. I never saw him again. For my first week, my mom drove me, and during that first week, when a radiation therapist asked how I was feeling, I answered her. My mom said, "Oh, she doesn't know what she's talking about. It's not from the radiation. Yeah, it's probably just because of her nerves." And it probably was, but I got the sense that my parents just wanted everything to be fine. I didn't feel as if my opinion mattered, because I was being talked over anyway. Because I wasn't going to be experiencing side effects that soon, my mom went back to the States to work since I didn't need her. My dad decided that he couldn't afford to take the time off work to take me to my appointments. I got set up with a volunteer driver four days a week. Depending on how many people were coming from my area to Large City, I might have to leave first thing in the morning to get there for the first appointment, and wait until the last appointment. If there was four of us, it was an all-day event. If it was just me, I could go to school for the first two classes, have lunch and then my next class, and then I'd miss my final class of the day. Every Monday the lady who became more like an adoptive mother to me drove me.

Since my review appointments were normally on Tuesdays, I went to every review appointment alone. I was the youngest person in the waiting room every day, reading the

Margaret Atwood book assigned for English class. Now if I smell a book that smells just like that book, my memory triggers and I'm back in the waiting room of the cancer centre again. It's very vivid. I think it's weird, but that's the way the brain functions.

My last week of radiation, the radiation oncologist told me that my skin might start getting really pink and sensitive after my treatments were finished, and if that happened, to contact him for prescriptions. I finished before Thanksgiving weekend, and they did a double dose for me that day – one in the morning and one in the afternoon - so that I didn't have to come back in for one more treatment the following week. That was the end of my constant, every day support, and I went back to school. My skin did start reacting pretty horrifically, and I called on the Thursday and asked for a prescription. They sent the order to the wrong city, and there was no way I could track it. The cancer centre didn't help me track it or replace it and I had to find someone locally to replace it. I'd only met the radiation oncologist four times and I really didn't have a rapport built with him.

When I came with the volunteer drivers, I would come hours early for my appointment. My appointments were always scheduled around 3:30, because that was the latest the volunteer drivers would pick you up or bring you for an appointment. And a 3:30 appointment gave me the chance to go to three-quarters of my school day. They would try and squeeze me in between patients. Having worked on a radiation unit as a student, I don't know how they did it, but thank goodness that they did. Every day the same female radiation therapist would come and get me out of the waiting room for treatment. I looked for her face every day. I can't remember her name, but every time she would come out for the next patient, I would look up as if to say, "Okay, is it my turn?" I was very anxious, looking back at it now. I always sat in the same spot so I could see her come out. She would either indicate that it's not my turn yet, or hold up a few

fingers to tell me how many people were ahead of me. She was the most support I had. She'd talk to me about school and how things are going when we walked into the room. She had a very calming effect. Once she called my name and we were walking in, I don't think I was anxious anymore.

The doctor and nurse didn't really emphasize the skin reaction. They said I might be tired, or a little nauseous, because it was the back of my neck, close to the base of my brain. I still don't know how big my treatment fields were or what exactly was treated. I've asked for that information, and no one's been able to provide it. And sore, dry throat. As for scarring, I lucked out, it's not noticeable. It was the very back of my neck, right at the baseline of my hair. I don't know how long the actual treatment time was. Since they told me I needed to be still, I would lay down in my mask, close my eyes and just listen. I blocked everything out.

While I was on treatment I told myself that this is what I have to do, I'm going to do it, and I'm just going to keep going. I had applied to university, I was trying to finish high school, and I didn't want to be ostracized any further, because I already felt as if people were always staring. Once the side effects kicked in and my hair started falling out, I wore a scarf to cover it up. One day a chunk of my hair fell out in my data management class. A girl sitting behind me tapped on the shoulder with this look of disgust on her face and then pointed at a chunk of my hair on the floor. I discreetly picked it up, walked to the front of the classroom, put it in the garbage can, walked right out the door, and didn't even grab my books. I don't know if I cried when I left the classroom. I can't remember. I just remember leaving, and I didn't go back. I picked up my books at the end of the day.

Some weeks I wouldn't attend school for the entire week. When I did go back to school, the teachers gave me a copy of someone's notes, and the assignments and tests to make up. I taught

myself through the last year. Again, I didn't write the final exams, because during exams I was back in the hospital and on bed rest for my final surgery, so they averaged out my final grade.

Once the radiation treatment was done, I had various appointments with the surgical oncologist and a plastic surgeon to plan the surgery. They didn't have office hours on the same day, so I was in Large City two days a week every few weeks for my appointments and pre-op visit. I went by myself every time I saw the surgical oncologist.

The plastic surgeon was wonderful at explaining things, but as far as permanent issues, none were really ever brought up. And same thing with the radiation – as far as permanent issues, I was specifically told not to expect anything. I had surgery June 15th. The video store chain was starting to go out of business and my boss called two days before my surgery to tell me that he was laying me off. I was an easy target since I was going to have surgery.

The day of the surgery we left at 3:00 a.m. to be in Large City for 4:30 in the morning for the pre-op. My surgery started at 7:00 a.m. Before the surgery started, I had one final meeting with the surgical oncologist to finalize his plan, and another final meeting with the plastic surgeon. She explained the two options and had me sign the consent forms for both, just in case the first option didn't work.

I was moved to a room in the evening. After my family got me settled into my room, they left for the day. On the third day, a nurse made me get up and start walking, because I hadn't been out of bed yet. I didn't have function in my arm. When I woke up, I couldn't move my left arm at all. All I could do was move my fingers so I used my fingers to drag my arm around. If I needed my arm up on the table, I'd pick it up with my right hand and put it on the table.

One option, (A) was relocating the muscle in my back and the other (B) involved taking the muscle from the leg. They told me the details after, when I started asking about all the back

pain. I asked if the pain would've been the same if the graft came from my leg. They said, "No. You'd be having all those issues in your leg, plus issues in your back, and your scars would be much more significant." The scars are what got me. I had a lot of issues with body image over the scars on my back and neck.

It was summer. No swimsuits or going in the sun, because the surgical scars were too tender. My boyfriend started treating me like I was fragile crystal. He was really afraid of hugging me or laying next to me, because he didn't want to hurt me. It was hard for both of us. Not being allowed to ride horses was hard. Retraining my arm how to move was really difficult. I got movement from my elbow down within two weeks, but it took all summer before I could really move my shoulder properly. But I had quite a lot of swelling and fluid retention, which also hindered my ability to move my arm at my shoulder.

The surgery shortened the tendons and ligaments in my neck that extended down into my shoulder. Moving certain ways would pinch muscles. They suggested I go to physio but all three physiotherapy places in town told me that they didn't know how to help me because the muscle locations were transposed. I just tried to move my arms the way I would every day. I increased my strength with everyday tasks. It wasn't until I was in the radiation therapy program at university and I met the physiotherapist at the cancer centre in Small City that I got help. She got me in as a patient and my physio was completely covered. I went to her twice a month and she showed me different exercises to stretch out the nerves and the ligaments the best I'll ever be able to, so that my shoulder and neck aren't getting pinched when I try to put on a sweater, or if I stretch and put my arm above my head. She showed me different exercises to try and retrain muscles to put my shoulder back into position.

I have horrible posture now which affects my back. It hurts so much and it aches every

single day. I am fighting chronic back pain, which makes me emotionally and physically fatigued. It distracts me when I'm trying to write an exam or complete a task. Those are the main issues, other than learning about the chance of developing a second cancer from the radiation and my fear of recurrence. It's not, IF I will develop cancer again, but WHEN. That's always in the back of my mind; I try to block that out. The daily physical pain is hard to block out.

It was a regular follow-up visit for the first little bit, and it was always with the surgical oncologist. As time went on, it was no longer with him but with another member of his team. I went to appointments regularly for the first three years. I was supposed to be seen every six months and now it's once a year. In April of this year, he said, "It's been five years, so you're officially cancer free." I'll see him again next April.

Body Art. After I finished university I celebrated by getting a tattoo to symbolize what I went through. My tattoo is on my left forearm. It starts at my wrist and goes up just over my elbow and almost wraps all the way around my forearm. There are three different stems.

The first two stems go into two different carnation flowers. The carnation is the flower of January, the month I was diagnosed in. Above them is the largest piece in the tattoo – the rose. It runs from the middle of my forearm up through my elbow. The rose is the flower of June, the month I had my final surgery and they count my remission from. The third stem starts at the bottom and then branches off to either side of the tattoo as a vine because it's a sweet pea. The vine goes all the way around either side of the tattoo and up to the top with sweet pea flowers, and they are one of the flowers of April, which was the month of my last appointment when I got the all clear. The three stems start together at the start of my diagnosis, because *there's always a hope* for a cure. That's why the sweet pea, which is the last flower, also starts in the very beginning. It's on my left arm because, when I woke up from my final surgery, I couldn't use my left hand. It also covers up all the scars from various IVs while I was in the hospital.

Reflections. I would have liked to have been seen in person with somebody with me, because when you hear you have cancer, it's like being in a tunnel, and you don't absorb as much as you should.

I would like to have the opportunity to ask questions at the beginning, like, "What do you mean by *biopsy*? What does *malignant* mean? What do you mean by *tumour*?" Now I know that *tumour* just means "growth," and it can be benign or malignant. Tumour was a scary word, and now it's not.

I never expected to get that phone call, to hear that something could be wrong. I thought that the bump was gone, everything was fine and I was just going to have this little scar that nobody was going to notice. My scars don't bother me anymore. I own them. They are what makes me, me. I wouldn't change anything about them.

I would have liked to be told about different treatment options earlier. Instead of being told in March, "This is what we want to do and we want to do it now", being told in February, "Sometimes with a diagnosis like this, we may need to do more. If you want to read this material and come back with questions..." because nobody in my family has been touched by cancer. We didn't know we should be doing research about different treatment options. If a family member gets sick in future, we will. I was the family guinea pig.

I needed support options specifically for me. I was 17. I felt like I was an adult, but now being older, I realize I was still an adolescent and I had different needs than adults. I needed to talk to someone, I felt so alone.

I was not taken seriously. Speak to me directly. Long-term, what is this really going to do to me? And give me – even if it's a two percent shot – details of how bad can this possibly get? I want to expect the worst and hope for the best.

Postscript. After finishing my radiation therapy degree, I went to Large City cancer centre and got copies of my records. I read through them and I have a better understanding of my case. They didn't tell me that my final surgery was more than cleaning up the tumour bed from December. There were four tumours growing in its place! Patients shouldn't find out important things by having to request their records. I should have been told everything at the start. Or after that surgery, they should have said, "By the way, while we were in there, this is what we found..." But it turned out they did know there were tumours growing in my neck before the surgery, because they had done another CT scan and MRI a week before the final surgery, and the report said that there were tumours in the images.

Two Little Black Clouds. Erica's¹⁷³ Story.

It all started in December 2012, over the Christmas holidays, when I was visiting family in the prairies. I was 52 years old and a single, professional business woman in Large Town. I had lost about 25 lbs deliberately that year. I felt a large, hard mass in my lower right abdomen and I was concerned.

When I got home on January 3rd, I made an appointment with my family physician who promptly made me an appointment with a gynaecologist, Dr. A. I had a CT scan done in January 2013 that showed a 14 cm x 9 cm cyst on the right ovary, plus a 6 cm x 4 cm cyst on the left ovary. Even though I had a CT scan, we did not suspect that it was cancer. Because of my age, he asked if I wanted a complete hysterectomy, my fallopian tubes, ovaries, cervix taken out, just to reduce risk and I said yes.

I had surgery March 13th, 2013. My boyfriend and girlfriends who lived in town, and my sisters and parents who flew in from the prairies took turns caring for me in those first few

¹⁷³ Pseudonym

weeks. One of the cysts burst when he took it out so Dr. A did a number of peritoneal¹⁷⁴ washes at the time just in case it was cancer, to hopefully prevent any cancer cells being in my body. My checkup with him after surgery was not supposed to be for six weeks but they phoned within two weeks when the pathology was back and asked me to come into the office. I turned to my friend and said, “It’s cancer, because this is too fast.”

Even though I suspected it was cancer, I went in by myself. I was surprised and maybe a little shocked. I’d never had a cancer diagnosis before but I don’t recall feeling immense emotion about it. Dr. A, my gynaecologist was very gentle in the way he said, “You know, it is cancer,” and I said, “I knew that as soon as you phoned to tell me to come in that it was cancer.” He told me it was Clear Cell Carcinoma, which is a rare and aggressive type of ovarian cancer. When he visited me in the hospital right after the surgery he told me he found endometriosis, many ovarian cysts, as well as fibroids in my uterus, but I never had any symptoms. And that surprised him because he said, “You were like a warzone in there.” When I think back, there may have been some symptoms but ovarian cancer is a very quiet cancer. It doesn’t have a lot of symptoms or they may be masked by other things.

I’m a great Internet person so as soon as I knew I was getting a hysterectomy, I looked that up. And when he gave me the diagnosis of Clear Cell, I looked that up, too. That wasn’t such a good thing to do because it is a rare, aggressive cancer and the prognosis from the material on the Internet is not good. That was really concerning and so that caused anxiety as I worried about what that might mean for me.

He referred me to a medical oncologist in Small City, Dr. B, who then referred me to the gynecologic oncologist, Dr. C, in Medium City. But when Dr. B also felt something in my breast, because breast cancer is linked to ovarian cancer, she also wanted me to see Dr. D, a

¹⁷⁴ Lining of the abdominal cavity

breast cancer specialist. That was probably the one thing that freaked me out the most is that I'd have ovarian cancer and breast cancer at the same time. Fortunately, Dr. D said, "Oh no, it's just cystic breast. Nothing to worry about." That was a relief! However, now I know there's an increased risk of breast cancer.

When I saw Dr. C in Medium City my concern was that he was going to tell me I needed more surgery. There's a whole protocol for extensive surgery if you've been diagnosed with ovarian cancer and I did not want that surgery! I had already read on the Internet how much more would be taken out, lymph nodes and omentum¹⁷⁵ and all kinds of things. I didn't want lymphedema and all the other complications. But Dr. C said, "Nothing showed up in the peritoneal washes. You're healthy. I don't advise further surgery but I do advise six rounds of chemo just to prevent anything that might've been missed from growing."

I was off work for nine weeks with the surgery and worked part-time hours once my chemo started May the 5th with additional coverage from my insurance company. The first chemo really was fine and I had no nausea or pain. Fatigue set in after the second chemo. Through the whole six sessions I think I had neuropathy in one fingertip once and that disappeared. So, I really had no symptoms or no side effects except for the fatigue and low white blood cell counts.

The CT scan I had after the chemo was clear. After Dr. B moved away I was reassigned to Dr. C. My first follow-up appointment with Dr. C was April of 2016 and he ordered a CT scan and moved my visits to every six months because I had been three years clear in September. I had the CT scan September the 12th. When I saw him on September the 19th he told me there was a mass in my right kidney, and referred me to a urologist, Dr. D. It's a 3.5 cm mass. I already know from the Internet that there's an 80% chance it's cancer. But I need to know that it's not

¹⁷⁵ Lining of fatty tissue that covers and supports the intestines and organs in the lower abdominal area

the ovarian cancer in the kidney, and no one's told me that yet. I have to wait for a biopsy to find out.

I'm on the Large Town hospital board and I know a lot of people at the hospital. I had the MRI within two weeks. I don't know if there was any pull because I'm a board member but I've got an ovarian cancer diagnosis already. I just need to get some answers. At first Dr. D said, "I can take out your kidney, you've got two. People function just fine on one kidney," but now when I saw him two weeks ago, since my kidney function for both kidneys is perfectly normal, he said, "Why don't I refer you to a doctor in Large City to do the biopsy who also does radiofrequency ablation¹⁷⁶. Why don't we try to save the kidney?"

I am at a loss right now because my medical oncologist doesn't seem to be in the picture because there's no new cancer diagnosis yet, but I've already got my letter from him saying my next follow-up appointment is in April of 2017. I don't know if all the doctors are talking to each other. I'm trying to cover off those communication gaps myself. I know from my Board and Advisory work that doctors don't always communicate with each other, right? But if I'm a patient who isn't on a Board or an Advisory Committee I would have no idea. I'm not leaving anything to chance. I advocate for myself and I think as patients in the healthcare system we need to take care of ourselves too. The doctors are there for one thing but I need to do everything I can to get myself well also.

When I left Dr. C's office with the bad news, I walked out into the hall and broke down because it's like, "Oh my God, now what?" I remember Dr. C's hand on the door handle and him saying "good luck" as he talked about the urologist. I don't recall either him or the nurse asking how I was doing, was I okay, did I need a few moments? There was no offer of any other kind of support. I was left with the referral form to Dr. D and "good luck". The nurse just told me about

¹⁷⁶ Less invasive procedure than surgery using electricity to destroy cancer cells

the urine test and blood work I had to do. It is frustrating, and especially when I sit at the provincial cancer Advisory table and hear about the supportive things that are supposed to be in place, and I just had firsthand experience of that not happening. When you get bad news and there's not even a diagnosis yet, are you really hearing?

I'm the type of person who says, "I'm going to deal with this and move on." I try to live in the present. Waiting is frustrating when you know you have something in you again and you had something very deadly in you before. I just want it out, but then I think, "Okay, so it enabled me to retire two years earlier," which I'm thrilled about because the stress I'm going through is very real. I'm very happy just to think about taking care of my health and not have to think about the 2 million things I had to do at work.

I think the fear will always be with me. Every time I go in for my appointment to Small City, I'm anxious now that I know I have something else going on. So, now I've got *two little black clouds*. I'm living with this. I've got to take care of myself and there are things I can do to help my kidney right now, there's things I can do so that I don't get breast cancer, which I've got an 80% chance of getting. There's no history of ovarian in my family. I didn't know until I went to get genetic testing that pancreatic cancer is related to ovarian and breast. My grandfather did die of pancreatic at 65. My maternal grandmother died at 49 of breast. I've got a first cousin right now who's in stage 4 pancreatic cancer, still surviving.

Information should come from the doctor because I think if I heard it through another healthcare professional I wouldn't trust the information as much. With cancer, the person I need to talk to is the oncologist, and when I knew I was having surgery it was the gynaecologist. With this kidney mass, right now my primary contact is Dr. D and I'll work with him. The most caring doctor I had was Dr. B. They're all detached but they all cared. I get the information and action that I need out of them.

I bring my iPad in with me when I have questions but I am well-informed so nothing they told me has ever been a surprise, except this kidney mass. Every time I come across something I don't know, I Google it. I've been on an ovarian cancer forum from the beginning. Women from all over the world talk about exactly what's happened to them, their treatment and ask questions. I find women who have gone through what I am going through. We understand that the prognosis for Clear Cell ovarian cancer is not good, so we want to know that you can survive. We share our stories. It gives you hope to know some women have survived 15-20 years. Is it without recurrences? No, usually there are recurrences at some point but they're still living.

Appendix H

Summary of Codes, Categories, and Descriptive Statements

Code	Category	Descriptive Statement
SHOCK; WAITING; ANXIETY; INFORMATION	Emotional Need (Disorienting Dilemma)	Diagnosis SHOCK and ANXIETY while WAITING without support for INFORMATION and action
ANXIETY; LOSS OF CONTROL	Emotional Need	ANXIETY about LOSS OF CONTROL of their lives
STRESS; SUPPPORTING OTHERS; FAMILY AND FRIENDS	Emotional Need	STRESS of appearing strong for family and friends Importance of FAMILY AND FRIENDS to support physical, emotional and financial needs
FEAR	Emotional Need	FEAR (of the unknown) when first diagnosed, at times of transition (not knowing next steps or not feeling supported) and after treatment (recurrence)
INFORMATION; COPING; SELF-MANAGEMENT; DECISION-MAKING	Emotional Need/ Cognitive Need	Importance of INFORMATION about their illness, treatment and supports to their ability to cope, self-manage and make decisions
INFORMATION; NAVIGATING GAPS; ACCESS	Cognitive Need	Difficulties finding services (information) and NAVIGATING GAPS between services and the professionals they needed
INFORMATION; SUPPORTS	Cognitive Need	Not receiving INFORMATION about emotional, physical and financial supports available when they needed it
INFORMATION; TIMELY; CUSTOMIZED	Cognitive Need	Not receiving INFORMATION about their cancer and next steps when they needed it, and in ways they could understand it
MANAGEMENT OF SIDE EFFECTS; ACCESS; TIMELY	Relationship/ Physical Need	Importance of timely and effective MANAGEMENT OF SIDE EFFECTS (physical needs)
RELATIONSHIP	Relationship	Emphasis on the importance of their RELATIONSHIP with their doctors: family doctor, surgeon, medical oncologist, radiation oncologist
COMMUNICATION; VOICE	Relationship	Difficulty with COMMUNICATION (being heard or taken seriously by doctors) prior to diagnosis Difficulties with COMMUNICATION (asking questions and getting answers or information from doctors; understanding information from doctors) during diagnosis, treatment and after treatment
INFLUENCE CHANGE; VOICE	Empowerment/ Perspective Transformation	Desire to IMPROVE the EXPERIENCE of other people with cancer

Appendix I

Summary of Participant Behaviours, Needs, and Expectations

Participant	<i>Participant in Care/ Decision Making</i> Did the participant ask questions and express opinions about her care?	<i>Information Needs</i> How did the participant look for/ manage her own information needs?	<i>Emotional Support Needs</i> What were the participant's emotional needs? How did she receive support?	<i>Contextual Reality</i> What were the participant's practical support needs (PSN)? What was her sense of responsibility to others (SRO)?	<i>Role Expectations/Key Words/Themes</i>
Taryn	Asked questions and expressed care preferences from the outset	Sought and managed all information; Doctors and Internet (peers)	Described needing little emotional support; she received support from colleagues and friends	Because she was a single parent of a young son she had PSN and a strong SRO	Doctor-as-Partner/ Team/ Living with Cancer; *Advocacy
Eva	Asked questions and gained confidence to express preferences over time	Sought and managed all information; Doctors and Peers	Described needing emotional support; she received support from psychologist	Because she was married with young children her PSN were met but she had a strong SRO	Doctor-as-Expert/ Relationship-Trust/ Fear; *Advocacy
Erin	Initially reluctant to ask questions and gained confidence to speak up	Initially did not seek or manage information; Doctors and Peers	Described needing emotional support; she did not receive professional support	Because she was single she had PSN; she did not want to burden her parents or grown children	Doctor-as-Expert/ Relationship-Trust/ *Finding her Voice
Lorraine	Did not ask questions and accepted the doctor's decisions	Did not seek or manage information; Doctors and Peers	Described needing emotional support; she received support from her mother and a social worker	Since she lived alone she had PSN; she depended on her mother for information and emotional support	Doctor-as-Expert/ Dependent-Vulnerable/ *Seeking her Voice
Holly	Initially reluctant to ask questions and gained confidence to speak up	Initially did not seek or manage information; Doctors and Internet	Described needing emotional support; she did not receive professional or peer support	Since she lived at home and attended high school her PSN were met; her parents told her to act as if nothing was wrong	Doctor-as-Expert/ Independent-Vulnerable/ Hope; *Advocacy
Erica	Asked questions and expressed care preferences from the outset	Sought and managed all information; Doctors and Internet (peers)	Described needing little emotional support; but she did not receive professional support when she needed it	Her PSN were taken care of; she emphasized taking care of herself	Doctor-as-Partner/ Team/ Fear; *Advocacy

Note. *Advocacy or Voice are synonyms for the ability to advocate or speak for one's self and others. Voice also equates to Empowerment.

Appendix J

Conditions for Transformational Learning for Women With Cancer

Elements of Perspective Transformation <i>Adapted from Mezirow (1997)</i>	Conditions for Transformational Learning for Women with Cancer
For learning to be transformational:	Based on the women's illness narratives and the literature, for learning about cancer and treatment to be transformational:
The learner has full information	<ul style="list-style-type: none"> • The woman can choose if she is ready to receive information and how much she wants to receive at each transition point in care. • The doctor provides customized information about her cancer and treatment in a language (e.g. plain language) and way (e.g. oral, written, visual) she can understand. • The doctor verifies that the woman understands the information by using techniques like teach-back.
The learner feels free of coercion	<p>Even though doctors possess special knowledge and the power to provide or withhold care and treatment:</p> <ul style="list-style-type: none"> • The woman feels she can ask questions. • The woman feels she can choose whether to accept the care/treatment that is proposed or to ask for a second opinion.
The learner has equal opportunity to assume various roles in the relationship	<ul style="list-style-type: none"> • The woman is the expert of her symptoms, feelings and expectations. The woman is a learner about cancer and treatment modalities during each new phase of her illness and care. • The doctor is the expert on cancer and treatment modalities. The doctor is a learner about the woman's symptoms, feelings and expectations, and provides information, care and emotional support during each new phase of her illness.
Both learner and teacher reflect on assumptions	<ul style="list-style-type: none"> • The doctor presents a plan for treatment with the expectation that the woman will accept the plan. • The woman expects the doctor to offer both appropriate life-saving treatment and hope that she will return to wellness. • Both have time to reflect when their assumptions are different.
Both learner and teacher are empathetic and good listeners	<ul style="list-style-type: none"> • Women expect to form a relationship with their doctors that is based on mutual respect. This expectation can vary with the woman's prior experience with doctors and other healthcare professionals. • This respectful relationship requires a dialogue. Doctors ask open-ended questions to solicit patient concerns. Women ask questions and consider doctor's answers.
Both learner and teacher are willing to search for common ground	<ul style="list-style-type: none"> • The doctor and the woman can negotiate the type and timing of treatment through respectful dialogue when there is a difference in expectations.

Appendix K

Cancer Needs Dialogue Tool

Adapted from the AMA Ask-Tell-Ask Dialogue, (2016)

Ask	Ask me what I know (ask for my story) and what more I want to know.
	Ask me if I am ready to learn and if I need to have someone else with me.
	Ask me how I like to learn. (Ask me what information I need now, whether I need it in written or a visual form, would I like to attend a class, etc.)
Tell	Tell me what I need to know now in simple, everyday language I can understand.
	Give me additional written/visual/audio support materials to take away so I can review them later and share with my family.
	Tell me where to find the best sources of cancer and treatment related information if I want more information later.
Ask Again	Ask me to summarize what you told me and ask me if I need to know more.
	Ask me how I am feeling, what my concerns are and if I know where to find more support (professional and peer) when I need it.